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The United States has seen rising rates of opioid abuse, which have led to changing policies designed to curb opioid prescribing. These guidelines and policies generally exclude hospice and palliative care from prescribing restrictions. However, no studies to date have thoroughly examined the impact of these policies to identify if there are unintended consequences affecting opioid prescribing within hospice and palliative care.

This is the first known qualitative description study to explore the perceptions of hospice and palliative care clinicians on how the opioid epidemic and related policies are affecting opioid prescribing within the specialty. The study addressed the literature gap by answering the following two research questions: 1. How has the opioid epidemic and related policies affected opioid prescribing practices among hospice and palliative care clinicians, and 2. How do hospice and palliative care clinicians perceive patients' end of life care has been impacted by the opioid epidemic and related policies?

The research was guided by the Theory of Planned Behavior and used in vivo coding and content analysis to describe the phenomenon using the participants' own language. Findings from the study revealed that the opioid epidemic and related policies have had four categories of impact on the patient, clinician, nursing, and specialty. A total of 12 subcategories describe the nature of this impact.

THE OPIOID EPIDEMIC AND THE IMPACT ON OPIOID PRESCRIBING IN
HOSPICE AND PALLIATIVE CARE: A QUALITATIVE DESCRIPTION

by

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Approved by

Committee Chair

For my wife, Andrea

And my children, Mason and Ella,

Without whom this endeavor would not have been possible

APPROVAL PAGE

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“Inveniam viam aut faciam”

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CHAPTER I

INTRODUCTION

We must appreciate that severe constant pain will destroy the morale of the sturdiest individual. . . . But . . . we are often loathe to give liberal amounts of narcotics because the drug addiction itself may become a hideous spectacle. (Dr. Warren Cole, Pioneering Cancer Surgeon, Circa 1956)

Statement of the Problem

Substance use and addiction have long plagued Americans. However, recent decades have seen a rise in rates of opioid use and unintentional overdose deaths that reframe the context of a modern substance use disorder. In a 2018 report, the U.S. Surgeon General and the Secretaries of the U.S. Department of Health and Human Services and the Substance Abuse and Mental Health Services Administration suggested that the rates of opioid use have reached epidemic proportions (U.S. Department of Health and Human Services, 2018). The scope of this epidemic has resulted in enactment of policies at the state and federal level to curb the problem. These policies have resulted in a reduction in the numbers of opioids being prescribed (Jones, Bruera, Abdi, & Kantarjian, 2018). It is clear that the medical community is in the midst of transition, as society at large determines how to most appropriately manage pain in light of the addiction potential of opioid medications. However, opioids remain a mainstay for treatment of pain for patients nearing end of life (Gabbard et al., 2018). Potential unintended consequences of policy changes could have a detrimental impact on hospice

and palliative care patients by limiting access to opioids and increasing the prevalence of untreated symptoms or distress. If present, these unintended consequences could ultimately result in increased suffering at the end of life. Currently, no identified literature exists that descriptively characterizes opioid prescribing practices among hospice and palliative care clinicians and how these practices might have changed due to the opioid epidemic or state and federal policies.

Purpose of the Study

The purpose of this study was to descriptively examine opioid prescribing practices among hospice and palliative care clinicians as these practices relate to the opioid epidemic and associated policies.

Research Questions

This study asked the following research questions:

1. How has the opioid epidemic and related policies affected opioid prescribing practices among hospice and palliative care clinicians?
2. How do hospice and palliative care clinicians perceive patients' end of life care has been impacted by the opioid epidemic and related policies?

Significance of the Study

No current literature appears to exist that qualitatively describes the opioid prescribing practices among hospice and palliative care clinicians related to the opioid epidemic and associated policies. Given the prevalence of opioid prescribing in hospice and palliative care and the need for these medications to palliate the symptoms of patients nearing end of life, the lack of existing evidence exploring clinicians' perceptions of

opioids is a gap that warrants study. Should this study reveal that the opioid epidemic or policies have impacted opioid prescribing in the setting of hospice and palliative care, it may reflect that patients are being undermedicated or suffering as a result of unintended consequences related to policy or cultural changes intended to deter opioid misuse and overdose deaths.

Significance of the Opioid Misuse Problem

Despite representing nearly 5% of the world's population, Americans use nearly 80% of the world's supply of prescription opioids (Rummans, Burton, & Dawson, 2018). The increase in use of prescription opioids is associated with an increase in addiction (Kolodny et al., 2015). It is estimated that 25% of Americans who are prescribed opioids for non-cancer pain struggle with addiction (Centers for Disease Control and Prevention, 2017e). The increase in use of prescription opioids has also been correlated with an increase in use of illicit opioids, overdoses, and unintentional deaths (Centers for Disease Control and Prevention, 2017d). Nationally, drug overdoses now represent the number one cause for accidental mortality, even surpassing motor vehicle accidents (Centers for Disease Control and Prevention, 2017a). The soaring rate of overdose deaths may be a causative factor for a declining national life expectancy, particularly among white Americans (Gomes, Tadrous, Mamdani, Paterson, & Juurlink, 2018).

Such a prolific and frequent misuse of opioids is associated with unintentional overdoses, whose prevalence has continued to increase over time. Specifically, from 2000 to 2010, unintentional overdoses from opioids increased 400% in the United States (McHugh, Nielsen, & Weiss, 2015). Unfortunately, many of these overdoses result in

death. Since 1999, more than 183,000 Americans have died from opioid related overdoses (Centers for Disease Control and Prevention, 2017d). Between the period of 2010 to 2015 the national death rate from drug overdoses increased from 12.3 to 16.3 per 100,000 (Rudd, 2016). The prevalence of overdose deaths increased again in 2016 to 19.8 per 100,000. In 2017, the last year data is available, the age-adjusted rate of opioid overdose deaths in the United States increased to 21.7 per 100,000 individuals (Centers for Disease Control and Prevention, 2017b). However, some research suggests that rates of overdose deaths related to opioids may be 20 percent higher than currently reported (Ruhm, 2017). National and regional surveys of substance abuse rely on self-reporting. Failure to capture true prevalence is likely to be related to inaccuracies with self-reporting due to the sensitivity of the topic.

States with the highest rates of overdose deaths are located in the Appalachian and surrounding regions including Western North Carolina. West Virginia has the highest rate nationally with 57.8 per 100,000 individuals dying from drug overdose (Centers for Disease Control and Prevention, 2017d). Approximately 26 states, including North Carolina saw significant increases in rates of opioid-related overdose deaths in 2017 compared to 2016 and subsequent years (Centers for Disease Control and Prevention, 2017b). The demographics of the opioid epidemic are comparable to trends associated with overdose. Nationally, in 2017, 67.5 percent (28,498) of overdose victims were male and 79 percent (33,450) were white, non-Hispanic. Individuals aged 25-54 are disproportionately affected by this epidemic and collectively account for 45 percent of all opioid related overdose deaths (The Henry J. Kaiser Family Foundation, 2017).

Data from the 2016 National Survey on Drug Use and Health suggest that over 28.6 million Americans aged 12 or older are active users of illicit drugs (or used an illicit drug within the past thirty days). This accounts for all illicit substances (e.g. stimulants, sedatives, opioids, methamphetamines, hallucinogens, etc). Although, a majority of these individuals reported marijuana use as the primary illicit drug, in some states it is now legal. Surveys now show that a majority of opioid misuse in the United States occur with prescription opioids (e.g. oxycodone, hydrocodone, morphine, etc). Prevalence of opioid misuse has continued to climb with each annual survey. In 2014, it was reported that 1.9 million Americans had an opioid use disorder primarily related to prescription medications. In 2014, an additional 586,000 individuals reported an opioid use disorder involving heroin (Substance Abuse and Mental Health Services Administration, 2017b). In the 2016 National Survey on Drug Use and Health, approximately 11.5 million Americans over the age of 12 reported misuse of prescription opioids. In 2016, an additional 948,000 individuals used heroin (Ahrnsbrak, 2016). A majority of respondents (62.3%) reported that they were taking opioids to treat pain. Approximately 12.9 percent of respondents reported misuse of opioids to feel good or get high. Other commonly reported reasons included relaxation (10.8%), helping with emotions (3.9%), helping with insomnia (3.3%), and experimentation (3%) (Ahrnsbrak, 2016).

Historical Background of the Opioid Problem

An understanding of the problem of opioid use in America is rooted in a complex historical context. National data show that the upward trend of opioid overdose deaths began in the 1990s and have spiked significantly in recent years (The Henry J. Kaiser

Family Foundation, 2017). The etiology of this trend is likely multifactorial. The 1990s were a decade marked by a national movement in the medical and nursing communities to better identify and treat pain in the clinical setting (Baker, 2017). Pain control was seen as generally lacking and in need for standardization. Guidelines were created identifying effective pain control as a patient right and pain management became a significant measure for quality improvement. As such, many accrediting organizations and healthcare systems (e.g. U.S. Department of Veterans Affairs and Joint Commission) adopted protocols naming pain as a fifth vital sign (Baker, 2017). This policy served to ensure that bedside providers were asking about pain control and offering treatment when appropriate. Clinicians were taught that there were no objective indicators for pain and to rely solely on the subjective report of the patient. Subsequently, patients' perceptions of their pain and adequacy of treatment became questions used to assess the clinical experience in post-hospitalization surveys (Baker, 2017). Through these systemic changes, the pendulum for control of pain management swung heavily to favor patients and resulted in more liberal use of opioids in clinical settings (Kolodny et al., 2015).

The 1990s were also a decade heralded by heavy marketing on the behalf of the pharmaceutical industry to promote opioid prescribing (Kolodny et al., 2015). In 1996, Purdue Pharma released OxyContin, a long-acting variation of oxycodone (Netherland & Hansen, 2017). OxyContin would eventually become the leading opioid prescribed in America and would gross Purdue Pharma \$31 billion over the next decade (Van Zee, 2009). Nationally, oxycodone prescriptions increased nearly 500% between the years 2000 and 2015 (Kolodny et al., 2015). To achieve this success, Purdue Pharma initiated

an effective marketing campaign to convince prescribers that OxyContin was non-addicting (Kolodny et al., 2015). It was later discovered that leadership of the family owned pharmaceutical company were aware of the addicting nature of their opioid product. As a result, in 2007, the company and three top executives plead guilty to federal charges of misleading the public and were fined \$634.5 million (Kolodny et al., 2015; Maxwell, 2011). However, OxyContin would continue to be extremely profitable and a commonly used method for management of chronic pain (Jonas, Young, Oser, Leukefeld, & Havens, 2012).

A shifting culture within the medical community to embrace opioid prescribing occurred despite a lack of sound scientific evidence to support the practice (Baker, 2017). Early evidence for chronic opioid prescribing was based primarily on two studies in the early 1980s, which found little incidence of addiction when opioids were used for the treatment of acute pain in burn units (Perry & Heidrich, 1982; Porter & Jick, 1980). However, these studies were cross-sectional and failed to assess for addiction with chronic use of opioids. A 1980 letter to the editor of the New England Journal of Medicine by Dr. Porter, a New York pain specialist was also frequently cited as evidence that opioids posed little risk of addiction (Leung, Macdonald, Stanbrook, Dhalla, & Juurlink, 2017).

These early studies allayed concerns from physicians and contributed in a shift toward experts recommending opioid prescribing for chronic pain (Baker, 2017). Increasingly, it has become clear that utilization of opioids to treat chronic, non-cancer pain is not substantiated by clinical research (Centers for Disease Control and Prevention,

2017c). To the contrary, it is now widely understood that opioids, when used chronically can be harmful and should be avoided (Jamison, Sheehan, Scanlan, Matthews, & Ross, 2014). In 2016, the Centers for Disease Control and Prevention (CDC) released new clinical guidelines that recommend minimizing dosing and limiting the duration of opioids to less than seven days of use (Centers for Disease Control and Prevention, 2017c). Additionally, many states including North Carolina are enacting policies designed to limit the availability of prescribed opioids (North Carolina Medical Board, 2017).

Many of the recent policies enacted at the federal and state level within the past few years (e.g. Comprehensive Addiction Recovery Act, SUPPORT Act, and NC STOP Acts) have had little time for evaluation of their effectiveness at curbing opioid abuse and prescribing. Although rates of addiction and overdose continue to climb, it appears that nationally, opioid prescribing reached its peak in 2012, when 81.2 opioids were prescribed per 100 people. As of 2017, this number had fallen dramatically, nearly 28 percent to 58.5 opioids prescribed per 100 people (Centers for Disease Control and Prevention, 2017e). The reason for this decline is likely complex and multifactorial. However, new policies and guidelines, and increased regulatory scrutiny are almost certainly influential in affecting provider willingness to prescribe opioids.

History of Federal Drug Policy and Response to the Opioid Epidemic

The current opioid epidemic is not the first within the borders of the United States. However, it is believed to be the worst, with more individuals affected by addiction and death than during any previous historical era. The etiology of the opioid

epidemic is complex and multifactorial and heavily influenced by public policy. Most researchers believe that the nature of current opioid addiction is largely iatrogenic due to increasing rates of opioid prescribing among physicians (Madras, 2017; Wright et al., 2014).

Iatrogenic causes of opioid addiction are not a new phenomenon. The late 1800s and early 1900s were a time when many physicians prescribed opioids (e.g. laudanum) to white women leading characteristically to frequent addiction within this demographic. A series of public policies were enacted such as the Pure Food and Drug Act of 1906, Smoking Opium Exclusion Act of 1909, and the Harrison Narcotic Act of 1914, which drastically reshaped the prescribing of opioids (Courtwright, 2009). The Harrison Narcotic Act initiated taxation and registration for any physician or pharmacist that respectively prescribed or dispensed narcotic drugs. Subsequently, these policies resulted in a drastic reduction in the supply of prescription opioids and led to a shift in use of illicit opioids for those with addiction (Courtwright, 2009).

The 1920s and 1930s were associated with the passing of more legislation to curb the growing illicit drug trade. In 1924, the Heroin Act was passed which prohibited heroin in all forms. The Narcotic Drug Import and Export Act was passed in 1922, which effectively regulated the drug trade (The National Alliance of Advocates for Buprenorphine Treatment, 2016). 1932 saw the passage of the Uniform State Narcotic Act, designed to create a uniform policy of drug regulation across the nation. In 1938, the Food, Drug, and Cosmetic Act was passed granting regulatory authority for the safety

and approval of drugs to the Food and Drug Administration, which was created in 1927 (The National Alliance of Advocates for Buprenorphine Treatment, 2016).

The 1950s and 1960s also heralded further drug reform policies. In 1951, the Boggs Act imposed strict criteria for prison sentencing for those convicted of drug crimes. The Narcotic Control Act of 1956 further increased the penalties established under the Boggs Act (The National Alliance of Advocates for Buprenorphine Treatment, 2016). In 1965, the Food, Drug and Cosmetic Act was amended to include other types of illicit drugs such as hallucinogens and stimulants (Quinn & McLaughlin, 1973).

The 1960s, 1970s, and 1980s were decades associated with significant change in federal drug policy driven by politicization (i.e. the war on drugs) and a culture embracing the criminalization of drug activity. The Controlled Substances Act was passed in 1970, which consolidated previous drug laws by categorizing all controlled substances into five schedules (The National Alliance of Advocates for Buprenorphine Treatment, 2016). The Drug Enforcement Agency was established in 1973 to be the primary agency tasked with enforcement of federal drug laws. The Narcotic Addict Treatment Act of 1974 allowed registration of methadone clinics for the treatment of opioid addiction. The Anti-Drug Abuse Act of 1986 increased the federal response to foreign drug trafficking, increased sentencing for drug offenders (particularly associated with crack cocaine), and improved funding for addiction treatment. The Office of National Drug Control Policy was legislatively created through the Anti-Drug Abuse Act of 1988, which also stipulated funding for the treatment of injection drug users who were

at high risk of contracting acquired immune deficiency syndrome (AIDS) (The National Alliance of Advocates for Buprenorphine Treatment, 2016).

The 2000s and 2010s were marked by a federal response to the growing opioid epidemic through policies designed to increase access to addiction treatment. The Drug Addiction Treatment Act (DATA) of 2000 allowed for physician registration to prescribe medication assisted treatment (MAT) in the community. DATA was later revised both through passage of new legislation and federal regulation to further expand access by increasing patient limits under the program (The National Alliance of Advocates for Buprenorphine Treatment, 2016).

Recent Policies Related to the Opioid Epidemic

The past several years have seen comprehensive policies enacted at the state and federal level to combat the opioid epidemic. The Comprehensive Addiction Recovery Act of 2016 is a federal law that incorporated many other pieces of legislation to expand access to treatment, prevention, and research for substance abuse (Whitehouse, 2016). Funding was provided through state grants designed to incentivize the development and proliferation of PDMPs and other tools to reduce opioid prescribing and diversion. Use of PDMP databases were further stipulated through passage of the federal Substance Use Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities (SUPPORT) Act, which was signed into law in November 2018 (Walden, 2018). This law mandates that prior to prescribing an opioid, a clinician must review a state PDMP database. Similar language is found in the North Carolina Strengthen Opioid Misuse and Prevention (STOP) Act, signed into law in 2017 (North Carolina General

Assembly, n.d.). The STOP Act also incorporates many of the recommendations found in the CDC guidelines for limited dosing and duration of opioids for acute and chronic pain. Both the federal SUPPORT Act and the North Carolina STOP Act have language that specifically excludes palliative care and hospice clinicians from many of the stipulations of the law that would likely be a direct burden to providing care. However, there is growing concern among some experts that increased utilization of PDMP databases, even if not mandatory, might reduce access to opioids even for patients that meet clinical indication (Finley et al., 2017).

Guidelines and Position Statements Related to the Opioid Epidemic

In 2016, the CDC released comprehensive guidelines regarding the treatment of acute and chronic pain. These guidelines discouraged opioid prescribing for chronic pain and recommended limiting morphine equivalent doses to less than 90mg per day, avoiding long-acting opioids, and tapering opioids as tolerable. The guidelines also encouraged prescribing naloxone (an opioid antagonist), urine drug screening, and frequent review of a prescription drug monitoring program (PDMP) prior to prescribing. Concurrent prescribing of an opioid with a benzodiazepine was also discouraged. It is noteworthy that these guidelines excluded hospice and palliative care, as it is clear that patients in these settings would have an undue burden given the need of these medications to ensure that symptoms are well managed (Centers for Disease Control and Prevention, 2017c).

Although these guidelines were voluntary and specifically excluded hospice and palliative care, some believe that the weight of the recommendations would still limit

access to opioids in this population. The American Medical Association released a position statement voicing concerns of unintentional consequences of the guidelines, as insurers and policy makers could potentially act to limit reimbursement and access to comprehensive pain management (American Medical Association, n.d.). Additionally, the American Cancer Society also released a position statement suggesting that the guidelines fail to address the cancer survivor, who might have chronic pain following treatment and continue to need access to opioids to palliate their symptoms (American Cancer Society, 2016).

The CDC guideline suggests tapering of opioids, which has possibly led to some clinicians rapidly tapering or discontinuing opioids in some patients (Darnall et al., 2018). A number of pain experts collectively signed an open letter to clinicians decrying the increasing practice of forcing patients with chronic pain to rapidly taper their opioids, which can potentially lead to functional debilitation, withdrawal symptoms, and possible illicit drug use. Consequences might even include suicide as reported in the Veterans Health System (Darnall et al., 2018). The leaders go as far as calling the trend a “humanitarian crisis,” which implies an ethical violation of the fundamental tenets of medicine and nursing of *primum non nocere*. Although, the article does not explicitly refer to patients or clinicians involved with hospice or palliative care, it is nevertheless an important article that addresses the conflicting aspect of the current medical response to the opioid crisis. Both palliative care and hospice providers are often at the forefront of managing pain, both in the inpatient and outpatient settings. It is often in collaboration with other medical providers that might feel it is prudent in the current prescribing

climate to rapidly titrate or discontinue a patient's opioids. This may worsen symptoms and diminish quality of life.

In 2018, the American Society for Pain Management and the Hospice and Palliative Nurses Association released a joint statement reaffirming the need for nurses to advocate for pain management and ensure appropriate treatment including opioids for those patients nearing end of life. In so doing, nurses fulfill their ethical duty to the patient. Both organizations appear concerned that there are many barriers that may potentially limit access to appropriate symptom management including changes to health care systems. Although not explicitly stated, changes made to health systems through policy or new guidelines risk unintentional barriers, limiting access to treatment (Coyne, Mulvenon, & Paice, 2018).

Factors Influencing Opioid Policy

Political factors. Historically in the United States, many drug policies were enacted to target drug offenses in minority populations. Examples of such policies include the opium smoking laws of the late 1800s focused mostly on Chinese immigrants, marijuana laws in the Southwest in the early 1900s biased towards Mexican immigrants, and cocaine laws in the 1920s targeting African Americans (Drug Policy Alliance, n.d.). Similarly, in 1971, President Nixon declared a war on drugs that politically targeted the liberal anti-war establishment protesting the Vietnam conflict and African Americans who had been recently successful in protesting social change through the civil rights movement. By creating federal policies that criminalized substances that were associated with these groups (e.g. marijuana in the case of liberal protestors and heroin in the case of

poor inner-city African Americans), the president used the powers of the office to shift the social narrative and discredit their respective social movements. John Ehrlichman, a top aide in the Nixon White House would later state that the president could not directly criminalize the social movement but through drug policies they could target and arrest the movement leaders thereby villainizing these groups in the eyes of the public (Drug Policy Alliance, n.d.).

Some perceive the war on drugs as being further escalated by the presidential election of President Reagan in 1981. Reagan effectively capitalized on social fears and developed a platform of a law and order specifically focused on drug crimes, particularly among minority groups. Nancy Reagan also influenced the national discourse surrounding drug use through development of the abstinence program of “Just Say No” (Drug Policy Alliance, n.d.). This national discourse resulted in a public hysteria surrounding drugs and crime. National polls revealed that over 68% of individuals in 1989 cited drugs as the number one national problem. This figure had grown dramatically from 1985, when only 2% of Americans cited drugs as being a top priority (Drug Policy Alliance, n.d.).

Federal drug policy during the Reagan era explicitly targeted drugs more frequently used by African Americans such as “crack” cocaine. The purported “crack epidemic” was primarily isolated within inner-city black communities due in part to the inexpensive nature of this cocaine derivative. Cocaine in powder form was more expensive and thus more widely used within white, affluent areas (Drug Policy Alliance, n.d.).

The war on drugs has had a profound impact on the African American population. Although African Americans are no more likely than white Americans to use drugs, African Americans are incarcerated for drug crimes at a rate six to ten times that of their white counterparts (Netherland & Hansen, 2017). Strict federal and state sentencing laws have disproportionally affected minority populations by often mandating minimum sentences for simple possession of an illegal drug. Soaring rates of minority incarceration mean that among middle aged African American men, more are likely to have been incarcerated than to have joined the military or graduated college (Netherland & Hansen, 2017). Both federal and state drug policies through the war on drugs have also often displaced the most vulnerable by disqualifying those with drug convictions from low income housing or jobs. This displacement of the vulnerable increased rates of homelessness, poverty, and crime (Matto & Cleaveland, 2016).

Social factors. The current opioid epidemic is a socially complex phenomenon that has many influencing factors. While the specific etiology is often tied to the increased prescribing of opioids among medical clinicians, the nature of addiction is rooted in a much broader phenomenological paradigm. Addiction is often referred to as a “disease of despair,” a term first coined by Princeton sociologists who noted that increased mortality among white, low-middle income, middle aged individuals was associated with overdoses, alcohol-related cirrhosis, and suicides (Case & Deaton, 2017). The nature of increased mortality in this demographic appears to reflect a trend of mental health disparity. However, the underlying nature of depression and despair is clearly rooted in a deeper sociological context.

Societal trends of addiction and overdoses are evident in a larger cultural context of helplessness, often in geographic areas that are associated with high rates of unemployment and economic distress (Case & Deaton, 2017). These trends are particularly evident in rural areas such as Appalachia (Meit, Heffernan, & Tanenbaum, 2017). In fact, Appalachia serves as a social epicenter of the opioid overdose epidemic. In 2015, opioid overdose deaths occurred in rural Appalachia at a rate 65 percent higher than the rest of the nation (Meit et al., 2017). Rural Appalachia is also an area that has historically been associated with higher rates of unemployment and poverty, particularly following the decline in industry, which long served as a primary driver for economic opportunity (Jonas et al., 2012). The loss of the coal industry and de-unionization of the jobs that are left have had a profound impact on the social structure of these rural communities. Coal jobs, which were often a guaranteed path to middle-class, served as a form of social capital in these communities. The loss of jobs, status, and income shifted culture and social capital to alternative forms. The sale, trade, and use of opioids and other illicit substances formed a new type of social capital that provided status and social hierarchy for members of affected communities (Jonas et al., 2012).

The illicit sale of opioids fueled an underground economy in communities that had few other economic opportunities (Quinones, 2016). A culture of opioid misuse and medication divergence has exacerbated the addiction phenomenon. Although the rate of opioid prescriptions is clearly related to addiction prevalence, many individuals misuse these medications without actually being prescribed opioids (Kuehn, 2014). A majority of those addicted to opioids first gained access to medications through family or friends

(Keyes, Cerdá, Brady, Havens, & Galea, 2014). Given the ample supply of opioids in a community via iatrogenic prescribing, there were many opportunities for those inclined to abuse these medications.

Technological factors. In the 1990s and early 2000s, at the start of the epidemic, opioid prescribing often occurred without the benefits of technology. Prescriptions were hand written, allowing for possible modification and forgery by a patient. Notations of prescriptions were made within a paper chart, making it difficult to reference historical information or dosing trends. Electronic medical records (EMR), now widely adopted, were less frequently used in that era by community physicians, many of whom were prescribing opioids. In 2011, national rates of adoption for EMR in primary care just reached 68 percent (Xierali et al., 2013). Electronic medical records allow a clinician to see the full clinical picture including how frequently medications are prescribed, adverse effects, and drug interactions. Utilization of an EMR also encourages sharing of information between clinics, which might discourage doctor-shopping or the deviant behavior of an addicted patient. Use of electronic prescribing through an EMR facilitates transfer of an opioid without a patient physically having the prescription. Such techniques facilitate patient care while mitigating risky behaviors. Research also suggests that an EMR provides an effective method of reducing opioid abuse by lowering the default pill counts associated with prescriptions (Chiu et al., 2018). The infrequent use of EMRs and the inherent lack of these benefits likely contributed to rising rates of opioid prescribing and abuse.

Prescription drug monitoring programs (PDMP) are a technology to discourage opioid abuse. Similar to lack of EMRs, early opioid prescribing lacked an ability to consistently coordinate the information to various prescribers and pharmacies. Patients could easily present to multiple emergency departments or physician offices complaining of pain, each giving a prescription for an opioid. This practice known as “doctor shopping” existed in an information vacuum. Many states have now implemented PDMPs as a database system to facilitate communication between prescribers and pharmacists and therefore discourage unnecessary opioid prescriptions. A prescriber is able to access the PDMP database and see that a patient has recently obtained an opioid from a different prescriber and can make the decision whether another prescription is clinically necessary. Pharmacists can also access the database and can contact the prescriber with concerns (Finley et al., 2017).

Technology in how opioids are manufactured has also had a role in both facilitating and preventing abuse. When OxyContin was introduced to the market in 1996, the drug was easy to crush, which facilitated abuse potential. Crushing of the long acting OxyContin altered the pharmacokinetics improving bioavailability through snorting or intravenous use. These unintended routes of administration facilitated the drugs euphoric effects and likely were a factor in increasing the desirability of the medications with addicted individuals (Lofwall, Moody, Fang, Nuzzo, & Walsh, 2012). The Food and Drug Administration has encouraged drug manufactures to incorporate tamper-resistance technology into medications that are at risk of abuse (Center for Drug Evaluation and Research, 2018). OxyContin was reformulated to include this technology

in 2013, which makes it more difficult to crush or change the intended route of administration. Tamper deterrence technology has been found to discourage abuse (Michna, Kirson, Shei, Birnbaum, & Ben-Joseph, 2014).

Legal and ethical factors. Increasingly, federal and state policies have been implemented to curb the rates of opioid prescribing in an attempt to reduce the prevalence of addiction, drug overdoses, and related deaths. Policies such as implementation of a prescription drug monitoring program (PDMP) have been associated with reduction in the rates of opioids prescribed by the medical community. For example, in 1999, when a PMDP was enacted in Kentucky there was a significant decrease in the numbers of opioids prescribed, leading to a reduction in the supply of these medications in affected communities (Substance Abuse and Mental Health Services Administration, 2017a). Other states have had similar rates of reduction when PDMP database were implemented (Finley et al., 2017).

Policies implemented to reduce the supply of prescription opioids have generally had some success in states most impacted by the epidemic (Haegerich, Paulozzi, Manns, & Jones, 2014). However, rates of addiction have remained widespread even as prescription opioids have become increasingly difficult to access. With fewer prescription opioids on the illicit market there has been a transition to other types of opioids including heroin (McHugh et al., 2015). Supply of cheap, black-tar heroin has flooded the market from Mexico and has met the existing demand in areas hardest hit by addiction. Unfortunately, heroin is often mixed with other substances including fentanyl and have

further exacerbated overdoses as the potency of the opioids are difficult to gauge (Quinones, 2016).

Drug laws and policy are grounded in the ethical principles and societal norms of the time. Many drug laws restrict one's natural autonomy to engage in behaviors that the society deems dangerous or culturally unacceptable. The ethical principal of beneficence is also evident in modern drug laws associated with access to naloxone, a reversal agent important for drug overdoses. Finally, the ethical principal of justice is increasingly discussed within society due to the history of drug policies disproportionately impacting minorities. The ethics of beneficence and justice are important ethical factors influential in ensuring that patients at end-of-life maintain adequate access to opioids if needed to ensure a pain free death.

Economic factors. The economics of access, availability and price of opioids and other illicit substances can significantly affect rates of addiction. Many policies are implemented with the goal of shifting the economics of addiction by reducing supply and raising prices, thus discouraging use (Rose, 2017). Research reveals that consumption of opioids is generally price-elastic, meaning that as price of a drug increases due to reduced supply, there is a proportional reduction in the demand of that product (Olmstead, Alessi, Kline, Pacula, & Petry, 2015). Economists and psychologists have determined that this elasticity supports a theory that addiction behavior still favors rational decision making. Rational addiction theory suggests that the past utilization of an addictive substance such as opioids, will inform the decisions of the addicted individual as they seek future supply (Caulkins & Nicosia, 2010). As a supply of opioids becomes scarce or expensive,

economic influences lead an individual to switch methods or substances to continue their addictive behaviors. An example of this phenomenon is the shift to heroin use in the United States, likely due to reduction and price fluctuations in the domestic supply of prescription opioids in illicit markets (Rose, 2017).

Poverty is a known risk factor for addiction (Matto & Cleaveland, 2016). The social stressors of poverty worsen one's ability to cope with or seek treatment for addiction. Subsequently, those in poverty are more likely to relapse than those with more affluent socioeconomic status. Poverty often limits options for addiction treatment by barring access to for-profit treatment centers or mental health providers that require medical insurance (Matto & Cleaveland, 2016). Like addiction, poverty is a risk factor for the cycle of despair and hopelessness characterized by concurrent mental illness and depression. Both poverty and addiction increase risk of police contact, incarceration, joblessness, and homelessness. These factors have a cyclical relationship whereby poverty exacerbates addiction and addiction exacerbates poverty (Matto & Cleaveland, 2016).

Data regarding the impact of opioid addiction on employment is conflicting. Some studies have suggested that over 50% of unemployed men report taking opioids, which could possibly reflect a correlation with opioid use and occupational injury. However, other studies have found that up to 85% of drug addiction treatment in the United States is covered under private health insurance, which likely implies current employment (Currie & Schnell, 2018). Regardless, data clearly show that opioid addiction can have a role in driving the economic output of those affected. The

Organization on Economic Cooperation and Development (OECD) recently reported that the opioid epidemic is likely partly responsible for declines in employment participation within the United States (Organization for Economic Cooperation and Development, 2018).

Use of Opioids in Hospice and Palliative Care

Opioids have long been used in hospice and palliative care to palliate symptoms. In this setting, opioids are primarily used for treatment of pain and dyspnea associated with advanced illness or the dying process (Blinderman & Billings, 2015). Opioid use among hospice patients is widely prevalent and medications are administered with the ethically justified goal of ensuring a “good death” (van den Beuken-van Everdingen et al., 2007). A recent study found that nearly 80 percent of respondents define a “good death” as being pain free (Meier et al., 2016). Historical data from the National Hospice Outcomes Project revealed that nearly 90 percent of patients were prescribed an opioid and 55 percent of these patients had a dose change at some point during their hospice care (Portenoy et al., 2006). However, despite the prevalence of opioid use among hospice patients, it is estimated that more than 75% of hospices under-treat or fail to properly manage pain (Herr et al., 2010). Older adults, such as those frequently seen by palliative care clinicians also frequently fail to receive appropriate pain management. These patients often have chronic comorbidities, polypharmacy, cognitive deficits, functional limitations, and medication sensitivity, which may lead to complications and concern among prescribers (Herr et al., 2010). For these reasons, pain among both hospice and

palliative care patients may also be difficult to appropriately assess and therefore might limit treatment.

There are data to support the efficacy of opioids used for managing pain in patients that are nearing end of life (Blinderman & Billings, 2015). However, more research is needed. When dosed appropriately, opioids used in the treatment of cancer pain can be given without significant side effects such as somnolence or anorexia (P. Wiffen, Derry, & Moore, 2014). Previous studies on the use of opioids for palliating dyspnea are few but do show clinical utility when administered orally or parenterally (Barnes, McDonald, Smallwood, & Manser, 2016). However, studies reveal that clinicians underutilize opioids in the palliative treatment of dyspnea, often due to fears of adverse effects (Verberkt et al., 2017).

Definition of Terms

Palliative care is often defined as a medical specialty focused on relieving suffering and maximizing quality of life for those with chronic or life-threatening conditions (National Institute on Aging, 2017). The World Health Organization and other national and international associations regard palliative care as involving the assessment and treatment of pain and other distressing symptoms (World Health Organization, n.d.a). Although it is generally agreed upon that palliative care focuses on symptom relief, the operationalization of this may differ significantly based on organizational structure and priorities. For the purposes of this study, palliative care was operationally self-defined by the clinicians' job description.

The definition of hospice is more concise and well defined than that of palliative care. Hospice refers to end of life care and includes a similar focus on comfort and symptom relief. Hospice care is operationally defined as being appropriate for those patients who are felt to have a life expectancy of six months or less (National Institute on Aging, 2017).

Pain is often defined as the subjective experience of discomfort related to tissue damage (Kumar & Elavarasi, 2016). Pain is recognized to be a complex phenomenon with multidimensional etiology rooted in physiological, emotional, psychosocial, and spiritual processes. Pain can be classified into acute or chronic by duration of symptoms. Pain is also commonly characterized by type (e.g. visceral, neuropathic, non-cancer vs cancer) (Kumar & Elavarasi, 2016).

Opioids are defined as a class of medications either chemically or synthetically derived from the opium poppy plant. For the purposes of this study, opioids refer to prescription medications regulated by the Controlled Substances Act. Examples of these medications include morphine, hydrocodone, oxycodone, fentanyl, methadone, codeine, and derivatives of these medications.

Clinicians are defined as a licensed physician or nurse practitioner working in the specialty of hospice and/or palliative care. All types of licensure and training such as osteopathy vs allopathy or adult-gerontology vs family, were included as long as the clinician currently practiced within the specialty of hospice and palliative care. Other clinician types such as nurses, social workers, pharmacists, and chaplains, although often

instrumental in forming a clinical plan that includes opioids, were excluded from this study as they are not licensed prescribers.

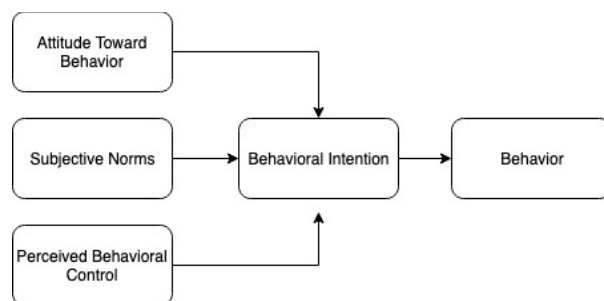
Methodology

A qualitative descriptive methodology was used to conduct this study. Interviews of hospice and palliative care clinicians were conducted to examine the research question. Qualitative description offers a method that is well suited for characterizing the phenomenon of interest. The methodological focus is on naturalistic inquiry, which allowed study within the hospice and palliative care environment in attempt to describe and characterize opioid prescribing (Kim, Sefcik, & Bradway, 2017; Sandelowski, 2000). Qualitative description is a method that allows thorough description of the phenomenon by those experiencing it (i.e. hospice and palliative care clinicians) and should help address gaps in the literature (Willis, Sullivan-Bolyai, Knafl, & Cohen, 2016). The method is particularly well suited for identification of a problem (Neergaard, Olesen, Andersen, & Sondergaard, 2009). The method is also appropriate for research that has limited time and resources (Bradshaw, Atkinson, & Doody, 2017). In the setting of limited previous research, qualitative description can serve as a structure to identify clinicians' perceptions of the opioid epidemic and barriers and facilitators to prescribing opioids. Although not explicitly identified, several studies examining topics surrounding opioid prescribing have utilized what appear to be qualitative description as a method (Click, Basden, Bohannon, Anderson, & Tudiver, 2018; Fleming, Bapat, & Varisco, 2018; Harle et al., 2015).

Theoretical Framework

The study was guided by the Theory of Planned Behavior (TPB). The TPB exists as a model for understanding behavior that is not fully under one's control. As such, the theory and the relationship of its constructs are useful in predicting most human behavior (Ajzen, 1991). In the case of conceptually understanding the impact of the opioid epidemic on hospice and palliative care, this theory has high utility given the hypothesis that the theoretical constructs of social norms, perceived control, and attitudes affect clinical decision making as providers decide whether to prescribe opioids. The theory has been used multiple times in the past as a conceptual framework to explain prescribing behaviors (Ali Murshid & Mohaidin, 2017). For the purposes of this study, the TPB was used to develop the interview guide.

Figure 1.1 The Theory of Planned Behavior (Ajzen, 1991)



The TPB specifies that the antecedents to intention will influence a behavior, making it more or less likely to occur (Ajzen, 1985, 1991; Montano & Kasprzyk, 2015). Factors that increase or decrease the positive or negative perception of attitudes, subjective norms, or control will be reflected in the behavior. In the case of opioid

prescribing in hospice and palliative care, attitudes reflect the internalized value that one places on the act. Previous research has shown that clinicians may feel concern regarding the prescribing of opioids (Childers & Arnold, 2012; Gardiner et al., 2012). The TPB suggests that these concerns of risk for addiction, adverse effects, or policies would reflect negative attitudes regarding opioid prescribing and would likely lessen the intention to perform the behavior. Pharmaceutical marketing may be a factor that also influences clinician attitudes toward prescribing (Ali Murshid & Mohaidin, 2017). Pharmaceutical marketing has been shown to be effective at shaping attitudes and affecting prescribing patterns, making prescribing more likely (Ali Murshid & Mohaidin, 2017). Pharmaceutical marketing is believed to have been an instrumental factor in promoting opioid prescribing and facilitating the opioid crisis (Kolodny et al., 2015; Van Zee, 2009).

Subjective norms, which are influenced through the formation of normative beliefs might also stem from the social dialogue and discourse one hears about an important topic. In the case of the opioid epidemic, national discourse heard on news, radio, or in social conversations could possibly influence the normative beliefs of an individual (Gardiner et al., 2012). If a hospice clinician works in a medical environment in which they hear colleagues speak negatively about opioid prescribing, the individual might perceive the behavior as being unsupported by their social group. To date, it appears that much of the current research suggests negative attitudes and subjective norms exist in outside medical specialties like primary care and the emergency department (Franklin, Fulton-Kehoe, Turner, Sullivan, & Wickizer, 2013; Harle et al.,

2015; Hooten & Bruce, 2011; Jamison et al., 2014; Kennedy-Hendricks, Busch, et al., 2016; Sinnenberg et al., 2017). However, it seems possible that given the necessary interaction among clinicians from different medical specialties, that attitudes and subjective norms could be influential even outside of a clinician's own peer group. Similarly, subjective norms might also be influenced by interaction the clinician has with their patients. Patient requests for opioids might increase the likelihood of prescribing (Oyler, Deep, & Chang, 2018). Interaction with a pharmacist might also contribute to the clinician's normative beliefs about the safety and efficacy of an opioids (Ali Murshid & Mohaidin, 2017). The TPB suggests that these social norms are influential on whether the behavior (i.e. opioid prescribing) is realized (Ajzen, 1985, 1991; Montano & Kasprzyk, 2015).

Perceived control, as influenced by control beliefs and perceived power, also influences the intentionality of a behavior (Ajzen, 1985, 1991; Montano & Kasprzyk, 2015). In the case of opioid prescribing, a clinician would be influenced by their perception of control over their clinical decision making. Control beliefs would also be influenced by factors that are perceived to make the behavior more difficult (Ali Murshid & Mohaidin, 2017). Policies and guidelines, if interpreted to be restrictive of opioid prescribing, might lessen the perceived control and subsequent behavior. Factors such as use of a PDMP, which is statutorily required in some states, has been shown to be perceived by some clinicians as a hassle or time-consuming to use (Click et al., 2018; Cushman et al., 2017). It seems likely that a clinician that feels restricted by the use of a

PDMP or similar policy would be less likely to demonstrate the behavior of opioid prescribing.

The construct of perceived control implies incomplete volition over the process of the behavior. Although clinicians wield substantial judgement in deciding the clinical plan, ultimately the scope of practice is determined regulatorily by outside agencies, including state and federal organizations. Clinicians who are fearful of regulatory oversight such as were identified in previous studies, might feel reduced control over their prescribing, which the TPB suggests would be influential in decreasing the behavior (Click et al., 2018; Cushman et al., 2017; Franklin et al., 2013).

Assumptions

The researcher for this study assumed that hospice and palliative care clinicians would be honestly willing to discuss their opioid prescribing patterns. It was also assumed that clinicians currently practicing in these settings would have an understanding of the opioid epidemic, even if they were not familiar with related policies. Additionally, given the theoretical framework, it was assumed that prescribers were influenced by a variety of external factors that are outside one's control.

Delimitations

This study is limited to:

1. Physicians and nurse practitioners currently practicing within hospice and palliative care settings in North Carolina. The limitation to a single state helped control for variation in state policies.

2. These clinicians must be involved in prescribing or recommending opioids for hospice and/or palliative care patients.
3. These clinicians must understand English.
4. All participants must be willing to be interviewed.

Summary

This study used a qualitative description method to explore hospice and palliative care clinicians' opioid prescribing practices as they relate to the opioid epidemic and associated policies. A qualitative descriptive study offers a method that may elucidate clinicians' perceptions of opioid prescribing and how these practices might have changed related to the opioid epidemic. It is the belief of the study author that contextualization of the phenomena would be best explored by interviewing those responsible for opioid prescribing. The study was guided by use of the TPB, a theoretical framework that can help explain intention to prescribe opioids. The study helps address a significant gap in the existing literature. Findings may help characterize prescribing patterns, beliefs, and concerns, among hospice and palliative care clinicians and identify possible unintentional consequences resulting from the opioid epidemic and drug policy.

CHAPTER II

OPIOID EPIDEMIC AND PRESCRIBING IN HOSPICE AND PALLIATIVE CARE: A REVIEW OF THE LITERATURE

Abstract

Context: Rising rates of opioid abuse worldwide have led to implementation of policies to curb opioid prescribing. It is unknown what impact these policies currently have on prescribing within the setting of hospice and palliative care.

Objectives: To determine the current state of the science of opioid prescribing in hospice and palliative care related to the opioid epidemic and related policies.

Methods: A systematic integrative literature review was conducted using the Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, ProQuest Central, and SCOPUS.

Results: A total of 54 studies were found in this review. A majority of the existing literature examines physician perspectives related to opioid prescribing in primary care settings. Ample evidence exists that policies can and do affect rates of opioid prescribing in primary care. Evidence suggests that opioids are necessary in hospice and palliative care to help manage pain.

Conclusion: Research is necessary to examine the possible impact of the opioid epidemic on opioid prescribing in hospice and palliative care.

Introduction

Recent decades have seen rising rates of opioid addiction, related overdoses, and deaths that have reached epidemic proportions (Dasgupta et al., 2014; Manchikanti et al., 2012). Although rates of addiction and overdose continue to climb, it appears that nationally, opioid prescribing reached its peak in 2012, when 81.2 opioids were prescribed per 100 people. As of 2017, this number had fallen dramatically, nearly 28% to 58.5 opioids prescribed per 100 people (Centers for Disease Control and Prevention, 2017e). The reason for this decline is likely complex and multifactorial. However, new policies and guidelines, and increased regulatory scrutiny are almost certainly influential in affecting patient access to prescription opioids and provider prescribing practices.

Opioids remain a mainstay for treatment of pain for patients nearing end of life (Gabbard et al., 2018). In the setting of hospice and palliative care, opioids are primarily used for treatment of pain and dyspnea associated with advanced illness or the dying process (Blinderman & Billings, 2015). Pain and subsequent opioid use among hospice patients is widely prevalent and is ethically grounded in the principal of a pain free death (van den Beuken-van Everdingen et al., 2007). Potential unintended consequences of policy changes could have a detrimental impact on hospice and palliative care patients by limiting access to opioids and increasing the prevalence of untreated symptoms or distress (Gabbard et al., 2018; Varilla, Schneiderman, & Keefe, 2015; Wilson, 2017). These unintended consequences could ultimately result in increased patient suffering. This paper explores the current state of the science of opioid prescribing in hospice and palliative care and how this might be impacted by the opioid epidemic.

Methods

An integrative literature review was conducted using the framework established by Whittemore and Knafl (2005). An integrative review is particularly useful as it allows for the inclusion of studies involving diverse methodologies (Whittemore & Knafl, 2005). For the purpose of this review, multiple online databases were searched including the Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, ProQuest Central, and SCOPUS. Consultation was also sought with a health librarian to ensure that search terms were comprehensive and not excluding viable databases. Keywords and medical subject headings (MeSH) used included palliative care and/or hospice; analgesic, opioid; prescribing, substance, and United States. Non-MeSH terms primarily consisted of synonyms and included prescribing patterns, analgesics, pain management, opioids, palliate, and policy. The terms epidemic and crisis were also searched given the frequency and formal use of these terms in referring to the current opioid problem. Searches were limited to the past ten years as this time period was felt to capture the national peak of opioid prescribing in 2012 and thus possibly reveal studies elucidating important trends. Inclusion criteria consisted of original research, related to the topic of opioid prescribing, that were published within the past ten years, and written in English. Given a limited number of results specific to opioid prescribing in palliative care and hospice, a wider search was taken to include articles involving other medical specialties, as it was felt that the prescribing practices, perceptions, and barriers of other specialties can inform both depth and breadth of the topic. Initially, international articles were to be excluded from this search as to better frame the national opioid problem and

its impact on palliative care. However, due to a limited number of results, the search was expanded to include international articles, which were felt to be relevant to explain prescribing within hospice and palliative care. It is noteworthy that although the United States is in the midst of an opioid epidemic, much of the world also has problems with opioid use and addiction (Manjiani, Paul, Kunnumpurath, Kaye, & Vadivelu, 2014).

A keyword search of “palliative care and opioid” revealed 1,756 articles published within the past ten years. This was reduced to 132 articles with the addition of “prescribing” added to the search criteria. The keyword search of “opioid prescribing and palliative care” revealed 130 articles, which was reduced to 86 with the addition of the criteria “not review” and further reduced to 19 with the criteria “United States.” The same search with “hospice” further located 28 articles. Searching the MeSH terms analgesics, opioid and United States located 1,470 articles, which was reduced to 226 with addition of “prescribing patterns,” and further reduced to 169 with the addition of “not review.” A similar search within CINAHL using key words “opioid prescribing,” limited to peer review, located 336 articles, most of which were also found in the PubMed database. The search criteria within CINAHL was narrowed using keywords “opioid prescribing and palliative care” and “opioid prescribing and hospice” and “United States,” which located 24 articles. The final number of articles included in this review was 54.

A search within SCOPUS found 96 articles using the above search criteria but none were considered relevant or were not previously located via other sources. ProQuest Central was used primarily to search dissertations that might be related to the topic.

However, no dissertations were found to be directly relevant. Article titles, abstract, and full text were screened for relevance and inclusion criteria to include in this review.

Results

Opioid Prescribing in Hospice and Palliative Care

There is a paucity of existing research exploring the specific impact of the opioid epidemic on hospice and palliative care clinicians or factors influencing prescribing. Only a single article was found directly related to the opioid epidemic and palliative care. A majority of related literature regarding the potential impact of the opioid epidemic on hospice and palliative prescribing are of case reports and expert opinion and therefore were excluded from this review. One study was found that looked retrospectively at the morphine equivalent dosing of medications prescribed by oncologists on patients referred to a palliative care clinic over six-year period (Haider et al., 2017). The study found that opioid dosing had significantly declined over the six years following increased regulatory and internal scrutiny. Specifically, from 2010 to 2015, the median daily morphine equivalent dosing decreased from 78mg to 40mg. The authors were unable to state unequivocally the cause for the decline but suggest it was likely due to increased regulations such as additional training required for the prescribing of long-acting opioids and review of a prescription drug monitoring program (PMDP) prior to prescribing. The authors note that at the time of this study, many of the regulations that were possibly influential in affecting prescribing patterns were voluntary and not yet mandated under state or federal law (Haider et al., 2017). Similarly, a study by Barbera et al. (2017) analyzed prescribing data of opioids between the years of 2009 and 2013 for cancer

patients in Ontario, following implementation of a mandatory province-wide pain assessment tool. Despite having increased pain assessment at times of patient contact with a cancer center and increased reports of pain, the rate of opioid prescribing actually decreased by five percent. The authors felt that the likely explanation for the reduced rates of opioid prescribing was fear among prescribers given increasing regulatory action in an era of the opioid epidemic (Barbera, Sutradhar, Chu, Seow, Earle, et al., 2017).

Haider et al. (2017) also found that over a six-year period, the type of opioid most frequently prescribed changed in relation to regulatory policy. The most frequent opioid prescribed was hydrocodone but during the period of time reviewed for the study this medication, regulated by the Controlled Substances Act, was rescheduled from schedule III (less restrictive) to schedule II (more restrictive). The authors felt that this regulatory change likely impacted the transition to tramadol as a preferred opioid for the oncologists at MD Anderson Cancer Center (Haider et al., 2017). Similarly, another retrospective review of hospital data found a significant reduction in the numbers of hydrocodone prescriptions given across a hospital system and a transition to codeine-based opioids and tramadol following the 2014 rescheduling of hydrocodone. The authors of this study note that regulatory restrictions might have unintentional consequences of transitioning to weaker opioids such as increased pain or adverse effects from codeine metabolites (Bernhardt et al., 2017).

A Need for Opioids in Hospice and Palliative Care

Not surprisingly, studies suggest that palliative care and hospice involvement are associated with opioid use (Borgsteede et al., 2009; Childers, King, & Arnold, 2015;

Heneka, Shaw, Azzi, & Phillips, 2018). Among cancer patients treated at a nursing home, hospice admission was associated with increased prevalence of opioid use when compared to patients not admitted to hospice care. However, among these patients, more than 60% were found to have pain, possibly indicating undermedication and a continued need for opioid access in these settings (Hunnicutt, Tjia, & Lapane, 2017). Conflicting data were found looking at a cross-sectional review of the 2004 National Nursing Home Survey which suggested that only 30% of nursing home residents admitted to hospice care had pain during the prior week and a majority of these nursing home hospice patients had access to opioids (75%) (Hanlon, Perera, Sevick, Rodriguez, & Jaffe, 2010).

Studies reveal that patients with cancer pain are often under medicated with opioids, particularly within the last twelve months of life (Barbera, Sutradhar, Chu, Seow, Earle, et al., 2017; Fisch et al., 2012; Gao, Gulliford, & Higginson, 2011; Ziegler, Mulvey, Blenkinsopp, Petty, & Bennett, 2016). These patients are often involved with palliative care. A retrospective chart review was done to find the prevalence of cancer patients that reported moderate to severe pain and yet did not receive an opioid. These patients were receiving palliative radiation, referred to treatment by oncologists and palliative care clinicians. Prevalence of undertreatment ranged from 28% to 40% over a period of six years (Kirou-Mauro et al., 2009). A prospective survey of over 3,000 cancer patients revealed that 67% had pain and over 30% were not being adequately treated with opioid analgesics (Fisch et al., 2012). The same study found that non-white patients were twice as likely to receive inadequate opioid dosing, likely related to providers' implicit biases involving opioid addiction and stoicism among minority patients (Fisch et al.,

2012). A study by Shaheen et al. (2010) found that errors were common in cancer patients and could lead to under-prescribing of opioids.

The availability, type, and strength of the opioid prescribed in the setting of hospice and palliative care is often dependent on the patient's prognosis and clinical trajectory (Borgsteede et al., 2009; Muir et al., 2013). A survey of 425 palliative care and hospice patients cared for by primary care clinicians revealed that 37% of patients who had a diagnosis of cancer were prescribed opioids three months prior to death and this gradually increased to 81% three weeks prior to death. Among non-cancer patients, 27% had a prescription for an opioid three months prior to death and this also increased to 64% of patients with a prescription for an opioid three weeks prior to death (Borgsteede et al., 2009). Borgsteede et al. (2009) also found that the potency of the opioid prescribed (as defined by the World Health Organization analgesic ladder) increased as the patient neared end of life. Similarly, the dosage and frequency of pro re nata (PRN) medications, including opioids, was found to increase as patients neared end of life (Russell, Rowett, & Currow, 2014). There is also evidence that referral to a palliative care clinic results in increased prescribing of long acting opioids (Muir et al., 2013). However, this study had a small sample of prescribers in a single palliative care clinic, so opioid changes might reflect prescriber preferences that are not generalizable outside that location (Muir et al., 2013)

Barriers and Facilitators to Opioid Prescribing in Hospice and Palliative Care

Evidence suggests that there are patient and clinician factors that can be a barrier to receiving pain management for patients in palliative care (Gardiner et al., 2012; Kwon,

Oh, et al., 2013). Gardiner et al. (2012) qualitatively studied provider perceptions to barriers involving palliative care. The authors found that many in primary care had fears related to prescribing opioids as patients neared end of life. Clinicians were most concerned when opioids were requested for the palliation of dyspnea or high dose opioids were required for the management of pain. Both palliative care and primary care clinicians identified education and experience with opioid prescribing as a potential barrier that could limit access. Clinicians who had limited education or experience were less likely to be comfortable with prescribing opioids. A theme emerged that primary care clinicians working with palliative care could facilitate the best access to opioids and specialty management of patient symptoms. Additionally, a barrier of patient and family perceptions was identified. Patient or family perception that opioids could cause addiction or administration lead to death were barriers to accepting treatment (Gardiner et al., 2012). Another study looking at a secondary data analysis and using the Barrier Questionnaire II as an instrument, found minimal barriers for patients receiving adequate pain management in outpatient palliative care (Kwon, Hui, et al., 2013). The authors found that of 196 patients, 96% were on a strong opioid and 63% of these patients were satisfied with their pain regimen. The authors suggest that at the time of the study, liberal access to opioids for palliative care patients might have resulted in minimal barriers in this sample (Kwon, Hui, et al., 2013). A similar study by the same authors but using a sample from a Korean hospital system found patient depression as a significant barrier to pain management (Kwon, Hui, et al., 2013)

The study by Gardiner et al. (2012) also identified media exposure and national discourse as a possible barrier to opioid prescribing among primary care and palliative care clinicians in the United Kingdom. The authors detail an example of a famous case of a physician serial killer who murdered patients using lethal doses of opioids. Focus groups revealed that the case was at the forefront for some clinicians making decisions when prescribing opioids. Clinicians worried about increased scrutiny and were more apt to rely on specialists such as palliative care to prescribe for patients nearing end of life (Gardiner et al., 2012).

Cagle et al. (2015) studied the efficacy of an educational intervention on alleviating patient and family barriers with opioids in the hospice setting. The intervention group showed decreased stoicism (e.g. perception of being viewed as weak), knowledge, and reduced barriers to pain management when compared to the control group. The authors found that barriers seemed more prevalent in African American caregivers, who reported increased stigma and fear associated with opioid administration. The intervention seemed particularly efficacious in alleviating these concerns among this demographic (Cagle et al., 2015).

Errors involving opioid prescribing, particularly in cancer patients are frequent and can be a barrier to adequate pain management (Heneka et al., 2018; Shaheen et al., 2010). A study by Shaheen et al. (2010) looked at medication errors in cancer patients as a way to support palliative care involvement as expert prescribers, possibly intervening in cases where patients were undermedicated. In a prospective survey of 186 cancer patients presenting to a palliative care clinic, at least 70% of patients had errors to opioid

prescribing frequency, duration, type, and dosage. Most of the errors found in this study (78%) were associated with providers failing to give around the clock opioids for pain control. The authors felt these errors could lead to poor pain control and felt that palliative care was an effective intervention to ensure appropriate opioid prescribing (Shaheen et al., 2010). Heneka et al. (2018) also found medication errors were common in both cancer and palliative care. Factors like clinician education or confidence were felt to have contributed to opioid prescribing errors (Heneka et al., 2018).

Setting of palliative care services and type of opioids used were found to be possible barriers to effective analgesia in a prospective cohort study in Germany (Müller-Busch, Lindena, Tietze, & Woskanjan, 2005). The authors found that patients that received palliative care services in the home were more likely to require a switch to a new opioid due to uncontrolled symptoms. Similar to other studies, patients with cancer were generally found to have poor pain control or were undermedicated. Adverse events associated with opioids, although rare, were also identified as a barrier to effective pain management (Müller-Busch et al., 2005).

Substance Misuse and Addiction in Hospice and Palliative Care

Palliative care and hospice clinicians have had to adapt to the opioid epidemic by incorporating guidelines and misuse screening into their practices (Childers et al., 2015; Merlin et al., 2018; Tan, Barclay, & Blackhall, 2015). Although opioid use might be clinically relevant, some patients remain at risk of misuse. However, data conflicts on how well or often clinicians perform screening for opioid misuse. Using a retrospective chart review, 114 patients at the University of Virginia Palliative Care Clinic were

assessed for opioid misuse risk using the Opioid Risk Tool. Authors found clinically significant risk with 43% of patients identified as having medium to high risk (Barclay, Owens, & Blackhall, 2014). In a national survey of palliative care clinicians who manage cancer pain, of 157 respondents, a majority were confident in managing opioid misuse in their clinics and routinely practiced risk mitigation strategies such as urine drug screening, checking PDMP databases prior to prescribing, and adhering to opioid contracts (Merlin et al., 2018). However, another survey of directors of palliative medicine fellowships found that although most programs incorporated substance misuse training into their curricula, a minority of programs had policies related to the routine screening of patients or families for misuse and diversion. Subsequently, use of urine drug screening and other risk mitigation strategies was generally infrequent (Tan et al., 2015). Another study used retrospective chart reviews to assess the prevalence of opioid misuse in a palliative care clinic. Although identification of possible opioid misuse was frequently identified on assessment, use of risk mitigation strategies was rare. Only four percent of 323 patients received a urine drug screen (Childers et al., 2015). Social Worker psychosocial assessments for 105 national hospice agencies were evaluated in another study to determine the characteristics of substance abuse screening. The study found that 68% of agencies performed some type of substance abuse screening for patients and families, yet the quality and type of these screenings differed by hospice agency (Sacco, Cagle, Moreland, & Camlin, 2017).

A study by Childers et al. (2012) found significant gaps in the education of palliative medicine physicians who were pursuing fellowship training. The study revealed

that treatment of opioid misuse was prevalent (77% had treated someone with a substance abuse disorder in the previous two weeks) and many reported having active concerns that patients were misusing medications. However, few (21%) of the physicians in this study felt comfortable with their training or ability to treat the symptoms of these patients (Childers & Arnold, 2012).

External Factors that Influence Opioid Prescribing Outside of Hospice and Palliative Care

Implementation of policies. There is research that suggests the implementation of policy at the organizational, state, or federal level is effective at reducing opioid access, particularly policies to encourage or mandate use of a PDMP database prior to prescribing opioids (Baehren et al., 2010; Bao et al., 2016; Gomes et al., 2014). Other research has showed inconclusive or limited impact on opioid prescribing following implementation of state PDMP programs (Barbera, Sutradhar, Chu, Seow, Howell, et al., 2017). However, using data from the National Ambulatory Medical Care Survey, Bao et al. (2016) showed a 30% reduction in the prescribing of schedule II opioids following PDMP implementation in 24 states. Following enactment of PDMP policy in Ontario, Canada, opioid prescriptions decreased by 12% in the first six months after implementation (Gomes et al., 2014). Kaiser Permanente, a large hospital and insurance system in California, saw substantial reduction in the numbers of opioids prescribed after implementing a comprehensive program, which included dispensing policies, drug monitoring, and follow-up procedures (Losby, Hyatt, Kanter, Baldwin, & Matsuoka, 2017).

Clinician perception of policies. Much of the research into clinician perceptions of policies is derived from survey data of primary care and emergency physicians. Physicians appear to have mixed views regarding policies aimed to improve the opioid epidemic (Click et al., 2018; Cushman et al., 2017; Franklin et al., 2013; Kennedy-Hendricks, Richey, et al., 2016; Knight et al., 2017; Sinnenberg et al., 2017). A study of Wisconsin physicians found that a majority generally had a poor understanding of policies affecting opioid prescribing that had recently been implemented in the state (Wolfert, Gilson, Dahl, & Cleary, 2010). Kennedy-Hendricks et al. (2016) found that a majority of primary care physicians surveyed were concerned with the significance and prevalence of the opioid epidemic. Most of the physicians in the study felt that the nature of the problem was the responsibility of those with opioid misuse disorders and generally supported policies increasing oversight of high-volume prescribers, mandating use of PDMP databases, and integration of opioid prescribing into electronic medical records. Conflicting views were found by Cushman et al. (2016) through a qualitative study of physicians and nurse practitioners. Themes identified prescriber concerns with regulatory scrutiny and the barriers of implementing policy such as time required to complete pain assessments and check a PDMP database prior to prescribing. Click et al. (2018) also found that clinicians generally felt that PDMP databases were a challenge and time consuming to use. Franklin et al. (2013) found only 25% of primary care clinicians surveyed were concerned about regulatory oversight. However, although a small percentage, nearly five percent of nurse practitioners surveyed planned to stop prescribing opioids due to regulatory changes. Another study found that 29% of primary

care physicians surveyed prescribed fewer opioids as a result of the increased regulations (Breuer, Cruciani, & Portenoy, 2010).

Clinician perception of opioid prescribing. Research suggests that physicians have a negative perception of addiction related to the opioid epidemic and subsequent opioid prescribing (Franklin et al., 2013; Harle et al., 2015; Hooten & Bruce, 2011; Jamison et al., 2014; Kennedy-Hendricks, Busch, et al., 2016; Sinnenberg et al., 2017). A survey of Texas family physicians found that attitudes regarding opioids were associated with willingness to prescribe. Although a majority of respondents (81%) of physicians felt that long-acting opioids would help in controlling chronic pain and would improve patient quality of life, a majority (78%) also felt that prescribing long-acting opioids would lead to increased regulatory scrutiny. Nearly half (51%) of physicians felt that prescribing long-acting opioids would lead to addiction. The study found that physicians who identified as being “unwilling” to prescribe long-acting opioids generally had less favorable attitudes regarding opioids (Nwokeji, Rascati, Brown, & Eisenberg, 2007). A study by Michael et al. (2018) found that clinicians in the emergency department setting generally had inaccurate perception of their own opioid prescribing habits and what they perceived to be group norms. Once identified, this lack of self-awareness could be corrected through intervention by showing the clinician their own prescribing data, which often led to reduced future opioid prescribing (Michael, Babu, Androski, & Reznick, 2018). A survey of clinicians at an academic medical center found that a majority felt that opioids were overused and more dangerous than other types of analgesia. This study also found that a majority of clinicians surveyed identified patient requests as a significant

factor in opioid prescribing and that resident physicians were the group most likely to feel pressured to prescribe opioids during the hospitalization (Oyler et al., 2018).

Knowledge deficits and lack of confidence regarding opioid prescribing are identified by clinicians as barriers to opioid prescribing (Franklin et al., 2013; Jamison et al., 2014; Pearson, Moman, Moeschler, Eldrige, & Hooten, 2017). Studies conflict in their assessment of clinician confidence. Jamison et al. (2014) found that younger physicians were more likely to have a knowledge deficit and subsequently lack confidence regarding opioid prescribing. Similarly, Pearson et al. (2017) also found a majority of clinicians lack confidence in managing chronic pain with opioids. However, a survey of primary care providers at the Veterans Health found a majority were moderately or strongly confident in their ability to manage chronic pain and prescribe opioids (Dobscha, Corson, Flores, Tansill, & Gerrity, 2008). Data show that as clinician confidence increases, concerns regarding opioid prescribing decrease (Macerollo, Mack, Oza, Bennett, & Wallace, 2014).

Clinician characteristics. Clinician characteristics such as race, sex, type of medical training, and years of experience can significantly influence opioid prescribing (Bartley et al., 2015). In the study by Bartley et al. (2015), female practitioners were more likely to show willingness to prescribe analgesia, particularly among non-White patients. Another study found that clinician authoritarianism, tied to political ideology, had an influence on opioid prescribing. Physicians who identified as being highly authoritarian were more likely to have negative perceptions of opioid prescribing and chronic pain patients. However, despite these negative perceptions and concerns, high

levels of authoritarianism was associated with increased rates of opioid prescribing than physicians with lower levels of authoritarianism (Burgess, Dovidio, Phelan, & Van Ryn, 2011).

The type of medical practice and specialty of the clinician is highly correlated with rates of opioid prescribing (Levy, Paulozzi, Mack, & Jones, 2015). In 2012, the year that rates of opioid prescribing peaked in the United States, primary care clinicians prescribed nearly half of all opioids. From a period of 2007 to 2012, the specialty that had the steepest decline (8.9%) was emergency medicine (Levy et al., 2015). Among Medicare patients visiting an emergency department between 2008 and 2011, a retrospective analysis revealed that despite having similar diagnoses, patients were more or less likely to receive opioids based on the physician seen. Physicians could be stratified into high prescribing or low prescribing categories, suggesting that physician characteristics were more influential than patient characteristics (Barnett, Olenski, & Jena, 2017).

Patient characteristics. Ample research shows that patient characteristics can influence a provider's willingness to prescribe opioids (Burgess, Nelson, et al., 2014; Burgess, Phelan, et al., 2014; Fisch et al., 2012; Spitz et al., 2011). Providers may perceive age as a barrier to opioid prescribing, particularly with geriatric patients (Spitz et al., 2011). A study of analgesia in the emergency department did not show any racial disparities with rates of opioid prescribing (Dickason et al., 2015). However, race has been shown in other studies to be a barrier to adequate pain management, especially for African American and minority patients (Burgess, Nelson, et al., 2014; Fisch et al., 2012).

Similarly, diseases with history of societal biases or stigma have been shown to be barriers to adequate pain management. This is particularly the case with patients infected with human immunodeficiency virus (Lum et al., 2011). The type of pain reported by the patient may also be a barrier. Clinicians are more likely to perceive chronic pain negatively (Dobscha et al., 2008; Hooten & Bruce, 2011; Wilsey, Fishman, Ogden, Tsodikov, & Bertakis, 2008). Despite these barriers, patients may have substantial influence over a prescribers willingness to prescribe opioids in the method and frequency by which they request prescriptions (McKinlay, Trachtenberg, Marceau, Katz, & Fischer, 2014). In a qualitative study of patients with chronic pain who access the emergency department, many identify feeling pain management and opioid prescribing was a fragmented process with poor communication by clinicians who did not always incorporate principles of inclusion and shared decision making (Smith et al., 2015).

Analysis

The perceptions and beliefs of hospice and palliative care clinicians regarding the opioid epidemic are unknown. It is possible that clinicians are experiencing unintentional pressures regarding their opioid prescribing from organizations, peers, or changing policy similar to what has been identified in other specialties (Hooten & Bruce, 2011; Jamison et al., 2014; Kennedy-Hendricks, Busch, et al., 2016; Pearson et al., 2017). However, research is needed to explore these perceptions to identify if a problem exists.

A majority of studies found in this review evaluate the opioid epidemic through the lens of a physician as prescriber. Studies that included other types of clinicians (e.g. nurse practitioners, physician assistants) had samples where these prescribers were a

minority. No study was found that looked at the problem through an interdisciplinary lens (e.g. nurse, social worker, chaplain, physician), which is a defining characteristic of hospice and palliative care. Hospice is an area that requires strong advocacy from nurses to ensure patients receive adequate symptom relief. Research is needed to understand the potential impact of the opioid epidemic on nurses' ability to fulfill the role of patient advocate. When nurses perceive that they are unable to fulfill their duty, it can potentially lead to moral distress and affect both clinical outcomes and job satisfaction (Epstein & Hamric, 2009). Some nurses may lack confidence or fear administering opioids to patient's nearing end of life (Coyne et al., 2018). It is possible that the discourse surrounding dangers of opioids might heighten this fear and lead to poor patient advocacy.

A majority of the studies found in this review were quantitative and used survey methodology. A majority of the qualitative studies found relating to opioid prescribing in hospice and palliative care were based in Europe. Although many of the factors relating to the domestic opioid epidemic are international such as substance abuse, addiction, and stigma, these international studies may not be fully representative or transferable to the United States. This clearly reflects a research gap.

Currently, there does not appear to be research exploring the intersection between the experience of the hospice or palliative care patient with pain and the evolving opioid epidemic. Additionally, research is needed on the experience of the caregiver of a hospice or palliative care patient in an era of the opioid epidemic. In the event of unintentional consequences to this population stemming from the opioid epidemic, it would be the

patients and caregivers who would be best suited to describing the phenomenon and consequences.

Discussion

The historical perception has been that opioid use for palliative care and hospice patients is safe and efficacious when appropriately administered and without significant risk of addiction (Pinkerton & Hardy, 2017). However, few studies on opioid safety exist in this population given that those patients who are nearing end of life are often excluded (Schenker, Merlin, & Quill, 2018). The perception of opioid efficacy and value for patients with limited life expectancy is reflected in the national discourse, policies, and guidelines. However, increasingly federal and state policies have been enacted, which have been shown to reduce opioid prescribing (Bao et al., 2016; Cushman et al., 2017; Franklin et al., 2013). Research is needed to identify the possible impact that these policies and the shaping culture surrounding the opioid epidemic might have on hospice and palliative care.

Of the 54 studies found for this review, only a few studies directly address the potential impact of the opioid epidemic on hospice and palliative care clinicians and the prescribing of opioids in this setting (Haider et al., 2017). Many studies relate to high risk patient populations such as oncology instead of hospice or palliative care (Borgsteede et al., 2009; Haider et al., 2017; Kirou-Mauro et al., 2009). However, the existing research does help elucidate the potential impact of policies that could limit opioid prescribing in this population. Research suggests that policies such as implementation of PDMP databases are efficacious in reducing opioid prescribing (Bao et al., 2016; Gomes et al.,

2014). Research also clearly shows that many patients with diseases typically followed by hospice and palliative care (e.g. cancer) are often undermedicated and yet continue to have pain syndromes requiring access to opioids (Barbera, Sutradhar, Chu, Seow, Howell, et al., 2017; Bernhardt et al., 2017; Fisch et al., 2012; Gao et al., 2011). There appear to be existing barriers to patients accessing opioids within hospice and palliative care (Cagle et al., 2015; Gardiner et al., 2012; Kwon, Hui, et al., 2013). Any policies that might further limit pain management to these populations might result in unintentional harm through increased pain and suffering.

It is evident that some clinicians in other settings such as primary care have negative perceptions of patients with substance abuse and chronic pain (Click et al., 2018; Cushman et al., 2017; Wolfert et al., 2010). These negative perceptions and policies implemented to combat the opioid epidemic can affect opioid prescribing (Bao et al., 2016; Franklin et al., 2013; Gomes et al., 2014). Hospice and palliative care patients are often cared for in partnership with clinicians from primary care and other specialties. Perspectives from these specialties is important to help develop the breadth needed to understand the full impact of the opioid epidemic on hospice and palliative care.

The lack of existing research into the impact of the opioid epidemic on hospice and palliative care has many gaps that need to be filled by research. A first step should be a descriptive characterization of the perceptions of those clinicians involved in prescribing opioids in hospice and palliative care. A benefit of hospice and palliative care is the provision of care using an interdisciplinary team. Research should also contextually explore opioid prescribing through the lens of this interdisciplinary framework. Next,

research should be undertaken to determine how, when, and why hospice and palliative care clinicians decide to prescribe or withhold prescribing of opioids. This information should help elucidate factors that facilitate or impede opioid prescribing within the context of the current opioid epidemic. Research should also be undertaken to see if there are relationships between state and federal policies and the number and type of opioids prescribed by hospice and palliative care clinicians. Ultimately research should characterize the impact that the opioid epidemic and policies have had on patients within the hospice and palliative care setting. This research will take time to develop and would occur in a highly dynamic social context with ever-developing policies. However, such research is essential to better understand how opioids are used to treat patients that are nearing end of life. Ideally such research might be used to help shape future policy, education, and clinical practice.

CHAPTER III

METHODOLOGY

Introduction

This qualitative descriptive study attempted to explore the impact of the opioid epidemic and related policies on opioid prescribing in the setting of hospice and palliative care. Opioids remain a mainstay for the treatment of symptoms as patients near end of life (Borgsteede et al., 2009; Childers & Arnold, 2012; Heneka et al., 2018; Hunnicutt et al., 2017). To date, a paucity of research exists exploring the perceptions of hospice and palliative care clinicians related to opioid prescribing and no research has been found that qualitatively describes this phenomenon as it relates to the opioid epidemic and/or rapidly changing policies and regulations. This study aimed to address this important gap in the existing health care literature. This chapter will describe the selected study methodology and rationale. Methodological decisions will be described including design, sampling, data collection, protection of human subjects, data analysis, and steps taken to improve the trustworthiness of the data. Potential study limitations will also be discussed.

Methodology

This qualitative descriptive study aimed to answer the following two research questions: 1. How has the opioid epidemic and related policies affected opioid prescribing practices among hospice and palliative care clinicians; and 2. How do hospice

and palliative care clinicians feel patients' end of life care has been impacted by the opioid epidemic and related policies?

Theoretical Foundation

Theory should guide the research question, which in turn guides the methodology chosen for the study (Creswell & Creswell, 2018). The Theory of Planned Behavior (TPB) offers a theoretical framework that conceptually explains the link between the intention to act (i.e. the behavior) and the constructs of attitude, subjective norms, and perceived control (Ajzen, 1991). This theory has been shown to be useful in predicting prescribing behaviors among clinicians (Ali Murshid & Mohaidin, 2017). The major theoretical constructs of the TPB provide a conceptual framework to understand how prescribing behaviors of hospice and palliative care clinicians can be affected by change in attitudes and beliefs. Increased regulatory scrutiny imposed by guidelines or policies, and a possible shift in values within the medical community would seem theoretically influential as factors that might also affect opioid prescribing among hospice and palliative care clinicians.

The TPB was used in creation of the interview guide. Questions were theoretically framed by the constructs of the TPB. Constructs of subjective norms, attitudes, and perceived control should be characterized through participant description of influences of culture, attitudes and internal beliefs about control over the prescribing process.

Design

Qualitative description was used to answer the research questions. This design offers a method that is well suited for characterizing the phenomenon of interest. Qualitative description is less interpretive than other qualitative methods and allowed the researcher to stay data near while comprehensively exploring the phenomenon (Sandelowski, 2000). The methodological focus is on naturalistic inquiry, which allowed study within the hospice and palliative care environment in attempt to describe and characterize opioid prescribing (Kim et al., 2017; Sandelowski, 2000). Qualitative description is a method that allows thorough description of the phenomenon by those experiencing it (i.e. hospice and palliative care clinicians) and should help address gaps in the literature (Willis et al., 2016). The method is particularly well suited for characterization of a problem (Neergaard et al., 2009). The method is also appropriate for research that has limited allocation of time and resources (Bradshaw et al., 2017). In the setting of limited previous research, qualitative description can serve as a structure to identify clinicians' perceptions of the opioid epidemic and barriers and facilitators to prescribing opioids. Although not explicitly identified, several studies examining topics surrounding opioid prescribing have utilized what appear to be qualitative description as a method (Click et al., 2018; Fleming et al., 2018; Harle et al., 2015).

Data Collection

The study accounted for an emergent design that allowed for change to the research process as needed to ensure a thorough exploration and description of the phenomenon of interest (Creswell & Creswell, 2018). The study design primarily

consisted of one-on-one face to face interviews between clinicians and the primary investigator. Remote interviews using telephone or skype was also considered if clinicians were to have difficulty scheduling time for a one-on-one interview. Remote interviews may also have been recorded digitally for transcription purposes. Recruitment and interviews continued until saturation was achieved. It was expected that some participants might be interviewed more than once. The interviews were estimated to take approximately one hour or less. The setting for interviews was conducive to audio recording and in a mutually agreeable location such as the office space of the clinician, library, or coffee shop. Interviews were audio recorded using two digital devices to prevent unintentional data loss due to device failure.

Demographic information was collected including age, sex, type of provider, and years of experience, and setting of practice (e.g. inpatient vs outpatient) to characterize the sample. An interview guide was used to guide the interview process. Interviews were semi-structured to ensure that key and relevant information was gleaned from the interview process. However, open ended questions were used to promote a rich narrative discussion with hope that the nuanced social context of the factors related to opioid prescribing would be elicited. Probing questions were used as a tool for clarification or to facilitate conversation. Collectively, questions were asked that would help elicit details regarding the clinician's attitudes and beliefs related to opioid prescribing within the setting of hospice and palliative care. The interview guide included the following questions, which were asked of each participant:

1. In your opinion, how has the opioid epidemic and related policies affected opioid prescribing in the specialty of hospice and palliative care? (TPB Concept – Attitude)
2. What factors are barriers or facilitators to you prescribing opioids in hospice and palliative care? (TPB Concept - Perceived Behavioral Control)
3. How would you describe the culture of opioid prescribing within your workplace? What about hospice/palliative care in general? (TPB Concept – Subjective Norm)
4. Do you intend to change your opioid prescribing practices as a result of the opioid epidemic and/or related policies? (TPB Concept – Behavioral Intention)

Additionally, when time permitted, follow up questions were asked, including:

1. Describe a situation in which you have cared for a hospice or palliative care patient that has uncontrolled pain and limited access to opioids. Was this situation affected by either the opioid epidemic or related policies?
2. Are you familiar with the North Carolina STOP Act and the CDC guidelines related to opioid prescribing? How might these guidelines impact opioid prescribing in hospice and palliative care?
3. Do you have any advice to other hospice and palliative care professionals prescribing in the era of the opioid epidemic?

Data Analysis

Data analysis was conducted concurrent with data collection to ensure that saturation occurred. Demographic data was collected and analyzed using descriptive statistics to characterize the sample. Directed content analysis using Erlingsson and

Brysieqicz (2017) framework was used to analyze the interview transcripts. Analysis used an inductive focus with in vivo codes in order to capture the participants own description of the phenomenon. Content analysis provides an ideal technique by which to characterize and describe the data and is commonly used as an analysis method for qualitative descriptive studies (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Kim et al., 2017). Content analysis allows a flexible approach that highlights the contextual factors that might influence the phenomenon of interest (i.e. opioid prescribing) (Vaismoradi, Turunen, & Bondas, 2013). A codebook was created allowing for consistency through the coding and analysis process. Coding occurred at the level of the sentence, which helped capture the ideas and contexts relayed by the study participants. Codes were clustered into categories and subcategories, which were then analyzed for conceptual relationships and description of the phenomenon. Findings were presented as major categories using exemplars from the coded data to provide descriptive evidence (Hsieh & Shannon, 2005). Microsoft Word Suite was used to facilitate data organization and coding (Hahn, 2008).

Sampling, Recruitment, and Setting

Inclusion criteria consisted of any physician or nurse practitioner currently practicing in a hospice and/or palliative care setting who prescribes opioids. Any clinician that had not had a recent (within three months) experience prescribing, managing, or consulting on care related to opioids for hospice and palliative care patients was excluded. It was not anticipated that any non-English speaking clinicians would be encountered. However, English as a spoken language was also used as an inclusion criterion.

Sampling was purposive using the snowballing technique via professional networks. The study was conducted in central North Carolina at organizations that provide hospice and palliative care services. Hospice and palliative care clinicians were sought after that work in inpatient and outpatient settings.

Ethical Issues and Protection of Human Subjects

Approval was obtained from the Institutional Review Board at the University of North Carolina at Greensboro. Informed consent was obtained from all participants. Confidentiality was maintained given the possible sensitive nature of opioid prescribing. Pseudonyms were assigned and used during the data collection to ensure that data were not linkable to any specific participant. All organizations represented by the study were masked. Sensitive data were aggregated. Data were transcribed using a transcription service with confidentiality agreements in place. Data were electronically stored in cloud-based storage provided by the University of North Carolina at Greensboro while adhering to data security protocols.

Participants of this study each received a \$20 Amazon gift card. Incentives are frequently used in qualitative research to ensure adequate sampling (Robinson, 2014). Although most research regarding clinician-derived incentives have involved ways to encourage physician participation in survey methodology, use of incentives in qualitative research are felt to be necessary to partially compensate clinicians for their time and ensure robust participation (Signorelli et al., 2018). Incentives with clinicians should be adequate enough to ensure response (Dillman, Smyth, & Christian, 2014). “Token” incentives that offer little value have not been shown to improve response rates among

physicians (Field et al., 2002). Use of gift cards of a reasonable amount should provide adequate compensation, while avoiding the potential introduction of biases found when the value of the incentive encourages research subjects to participate at the expense of truthfulness (Robinson, 2014).

Trustworthiness of the Data (Role of the Researcher)

A variety of techniques were employed to ensure study validity and reliability (Creswell & Creswell, 2018). An audit trail consisting of field notes, memos, and study decisions helped ensure credibility. Data were conveyed using rich narrative descriptions in the words of the study participants. Rich, thick descriptions are used to describe participant narratives to help ensure trustworthiness. Additionally, figures and tables help convey the study findings, which also establish trustworthiness (Elo & Kyngäs, 2008). Efforts were taken by the primary investigator to be reflexive in his views of the study phenomenon as to ensure that undue bias was not introduced during the study.

Bracketing was used to identify any preconceived biases that may have been held by the primary investigator of this study. Prior to initiating the study, the student researcher spent time reflecting on his own perceptions and biases related to the research questions. These thoughts were documented and available for reference during the data collection and analysis phases as to limit the risk of biased results.

Delimitations

This study was limited to:

1. Physicians and nurse practitioners currently practicing within hospice and palliative care settings in North Carolina. The limitation to a single state helped control for variation in state policies.
2. These clinicians must have been involved in prescribing or recommending opioids for hospice and/or palliative care patients.
3. These clinicians must understand English.
4. All participants must be willing to be audio tape recorded/interviewed.

Summary

This study aimed to fill a key literature gap by describing how the opioid epidemic and policies have affected opioid prescribing in hospice and palliative care. The study used qualitative description as a study design to ensure that contextual factors were explored through the attitudes and beliefs of hospice and palliative care clinicians who are engaged in opioid prescribing. The Theory of Planned Behavior was used to guide this study as it provides an ideal conceptual framework to explain the factors that affect intentionality to prescribe opioids. All reasonable methods to ensure ethical standards and protection of participants were adhered to throughout this study. Reliability and validity were maintained through use of an audit trail, bracketing, and use of an experienced qualitative researcher to confirm coding and analysis.

CHAPTER IV

RESULTS MANUSCRIPT

Background

Rates of addiction and opioid abuse have surged in recent decades resulting in the U.S. Surgeon General declaring the problem a national epidemic (U.S. Department of Health and Human Services, 2018). The opioid epidemic led to enactment of policies at the state and federal level to reduce patient access to opioids. Data suggest that these policies have been effective at reducing the number of opioids prescribed by clinicians (Jones et al., 2018). Examples of such policies include the guidelines introduced by the Centers for Disease Control and Prevention (CDC) in 2016 and the North Carolina Strengthen Opioid Misuse Prevention (NC STOP) Act of 2017. Collectively, these policies place regulatory pressures on prescribing clinicians and discourage use of opioids for chronic pain. However, opioids remain a primary method of palliating distressing symptoms for patients with complex, life-limiting illnesses, which are often managed in the setting of hospice and palliative care (Gabbard et al., 2018). Despite policy exclusions for hospice and palliative care patients, it is unknown if these policies may have unintended consequences affecting the prescribing practices within these specialties.

Previous studies such as the one by Haider et al. (2017) found a decline in opioid prescribing within a palliative care clinic between the years 2010 to 2015, likely related

to increased regulatory scrutiny. Additionally, the same study found the most frequently prescribed opioid for palliative care patients in an oncology setting changed to tramadol after the rescheduling of hydrocodone-acetaminophen by the Drug Enforcement Agency (Haider et al., 2017). Similarly, another study found that opioid prescribing decreased in a cancer center in Ontario, Canada, following implementation of a mandatory pain assessment tool (Barbera, Sutradhar, Chu, Seow, Earle, et al., 2017).

Multiple studies document that clinicians practicing in primary care and other specialties frequently have concerns about opioid prescribing and related policies (Click et al., 2018; Cushman et al., 2017; Franklin et al., 2013; Kennedy-Hendricks, Richey, et al., 2016; Knight et al., 2017; Sinnenberg et al., 2017). However, there is a paucity of research currently describing the perceptions of hospice and palliative care clinicians on the opioid epidemic and how related policies might influence their prescribing practices and clinical decision making. This study aims to help address this important gap in the literature by answering the following two research questions: 1. How has the opioid epidemic and related policies affected opioid prescribing practices among hospice and palliative care clinicians, and 2. How do hospice and palliative care clinicians perceive patients' end of life care has been impacted by the opioid epidemic and related policies?

Methods

A qualitative descriptive, cross sectional design was used to conduct this study. Given the focus on naturalistic inquiry, qualitative description is particularly well suited for identification of problems and characterizing the phenomena of interest (Willis et al., 2016). The Theory of Planned Behavior (TPB) was used as a theoretical framework to

guide the research. The constructs of the TPB (attitude, subjective norms, and perceived behavioral control) help explain potential factors that can influence behavioral intention to prescribe opioids (Ali Murshid & Mohaidin, 2017). The TPB was primarily used to guide the creation of the interview guide.

Study Participants

This study was approved by an Institutional Review Board. Participants were recruited purposefully using professional networks and snowballing. Inclusion criteria consisted of physicians and nurse practitioners currently practicing within hospice and palliative care settings in North Carolina who had been involved in prescribing or making recommendations for opioids within the past three months. Six physicians and four nurse practitioners (see table 1) agreed to participate and be interviewed in a location of their choosing. Participants were employed in three different agencies in central North Carolina and represented a variety of roles in inpatient, outpatient, hospice, and palliative care settings.

Data Collection

Semi structured interviews lasting 30 to 60 minutes were conducted with open ended questions and follow up probes were used to evoke participant responses. All participants were asked their perception of how the opioid epidemic and related policies have affected opioid prescribing in hospice and palliative care, to identify factors that facilitate or impede opioid prescribing, to describe the culture of opioid prescribing in their workplace and specialty, and if they had changed or intended to change their opioid

prescribing due to the opioid epidemic and/or related policies. Demographic data were collected from each participant.

Data Analysis

Interviews were audio recorded and transcribed verbatim for analysis. Content analysis occurred concurrently with data collection and continued until saturation was reached (Erlingsson & Brysiewicz, 2017). In vivo codes were used to characterize the phenomenon using the participant's own language. A codebook and Microsoft Word helped organize the data and facilitate the coding process. Codes were grouped inductively into related categories and subcategories.

Results

Four primary categories emerged during the analysis, which described the reported area of impact of the opioid epidemic and related policies on the patient, clinician, nursing, and specialty. Participants universally agreed that the opioid epidemic had influenced these four areas within hospice and palliative care, although the perceived scope and nature of the impact varied. Variation in perception seemed to differ by primary practice specialty (i.e. hospice vs palliative care) and setting (inpatient vs outpatient).

Impact on the Patient

All participants reported encountering patients that had poor pain control or limited access to opioids due to the opioid epidemic. Most participants used words like "serious pain," "terrible pain control," and "suffering" to describe these patients. The following statement seems to summarize the general sentiment among the group, "So,

patients who are nearing end of life, who may also have very heavy chronic disease burdens, they have to fight to get pain control. We see it time and time again.”

Additionally, half of the study participants felt that patients were being overly stigmatized or victimized in some way due to the opioid epidemic. Most of the stigma surrounded labeling by other members of the health care team with phrases like “drug seeker” or “drug addict” when patients verbalized pain complaints or requested opioids. Many participants spoke of encounters with patients where they had difficulty appropriately prescribing opioids due to patient or family fear of addiction. A majority of participants also identified experiences or concerns that patients would turn to illicit opioids due to uncontrolled symptoms.

We also have people who are using illicit drugs to control their pain because they can't get, uh, drugs in legal ways. They're taking it out of their relative's closet or they're having unusual urine drug screens because they're so desperate for this relief.

Impact on the Clinician

While study participants readily identified and spoke of the impact of the opioid epidemic on their patients, a majority stated that there had been few changes made to their individual prescribing practices related to the opioid epidemic or policies. Most participants identified strong personal beliefs related to the need for opioids in this patient population. Additionally, participants seemed to have the perception that their practices were safe and would continue despite a change in the practice behaviors of surrounding clinicians and the medical culture at large. However, half of the participants spoke of the

need to incorporate protocols and careful prescribing practices due to the opioid epidemic. Use of prescription drug monitoring programs, risk assessment tools, pain contracts, urine drug screens, and having an exit strategy were all identified as practices currently utilized by study participants to prescribe opioids in hospice and palliative care. Phrases like “I prioritize symptom management” and “I did it anyway” were used to characterize their willingness to continue prescribing. Some participants noted the iatrogenic nature of the epidemic but felt that their prescribing within the setting of hospice and palliative care did not contribute to the problem and therefore should not be subject to change.

I really don't look at [the epidemic] as a barrier. I mean there's a place for if it's indicated, its needed, I write it. I don't worry about, no, I don't worry about an epidemic and don't worry about any of that stuff because then you're going to maybe not give it to someone who needs it.

Impact on Nursing

Many participants spoke of nurses acting as strong advocates for effective pain control despite the perception that other members of the health care team often engaged in patient labeling and limited opioid prescribing. However, a majority of participants also discussed issues with perceived inappropriate nursing practices that resulted in patients not being administered opioids when needed. One participant stated:

I'm not getting any PRNs given and I'm walking in seeing somebody breathing 40 times a minute. I'm seeing a real lack of education no matter how many times I stress opioids are not just for pain. This is for this dyspnea. It's written on the orders to give on either, but I'm not getting them given.

Another participant expressed:

It's very distressing for the nurses when people can't get medicine that they think that they should get. Um, and you know, and I think that they're willing to try alternatives and do whatever. But I do think, um, they feel, they feel that they're the patient advocates.

In analyzing participant responses, it appears that the practice setting was particularly influential in the perception of nurses as patient advocates or contributors to the problem of poor symptom control. Participants who worked in the inpatient setting more often experienced problems with as needed medications not being given appropriately. Conversely, participants who worked in the community setting or hospice more often perceived nurses as patient advocates.

Impact on the Specialty

A majority of study participants reported feeling that the opioid epidemic had limited impact on patients within the hospice setting but that they had seen more impact within palliative care. Phrases like “the safest environment” and “victims are not hospice patients” were used to describe hospice as being marginally impacted by changes resulting from the opioid epidemic and policies. One participant described it this way, “People who go into hospice feel that end of life needs to be comfortable, whatever that takes and that it often requires opioids, so I do think that opioids are prescribed. I just, I don't think it's changed.”

Unanimously, study participants described organizational problems stemming from the opioid epidemic as having impacted inpatient and outpatient hospice and

palliative care. Primarily these problems arose from concerns with clinicians in other medical specialties. In the inpatient setting, participants often described having problems with hospitalists refusing to prescribe. Oncologists were also frequently identified as clinicians who were reluctant to prescribe opioids. One participant told of a patient with an advanced malignancy who presented to the hospital with an acetaminophen overdose due to a refusal from the oncologist to prescribe opioids. Another participant described an oncology group that no longer prescribes opioids and instead refers all patients for pain management to palliative care. Hospice clinicians also described being asked by referring clinicians to take over opioid management.

Palliative care clinicians were more likely to describe a lack of resources as a primary barrier to opioid prescribing. Clinicians in the inpatient setting described concerns with opioid management when there was no outpatient clinician willing to assume the responsibility upon discharge. One participant described it in the following way, “Can I find an oncologist, primary care physician, pain management specialist, somebody who feels comfortable enough or understands enough what my intent was to continue that whenever they leave here?”

The palliative care clinicians in the community also identified organizational structure as a primary barrier. These consulting clinicians engaged in opioid recommendations to the referring clinician and did not assume primary prescribing responsibility. They described frequent “push back” from the referring provider that might be unwilling to start or adjust a patient’s opioid regimen. Other participants

identified leadership concerns and a perception that they were not supported by their supervisors in the prescribing role. One participant described the following:

I was flat out told by my boss, you cannot do this. I'm telling you you can't do this. And I even said to him, you're telling me how to practice medicine? And he said, well, in this case I am.

Some participants voiced a belief that the broad definition of palliative care was a challenge in the setting of the opioid epidemic. Phrases like “we don’t know how to label” and “so it all goes to palliative care” describe these concerns. Other palliative care participants in both inpatient and outpatient settings, described an increased number of referrals for pain related issues due to an unwillingness by other clinicians to prescribe. One participant described it this way:

I think in the palliative care space that changes have occurred, completely. You know, palliative care services had been one of those first doors in which people with opioid addiction had been knocking on to, to, to see if they could get this ongoing prescribing because of PCPs have shut down the doors.

A majority of participants also identified regulatory factors related to the opioid epidemic as influential to the specialty of hospice and palliative care. Most clinicians were able to describe the CDC guidelines and NC STOP Act and knew that hospice and palliative care were excluded from many of the regulatory criteria. However, a majority of participants described the impact on outside medical specialties as still reverberating within hospice and palliative care. Many participants used the metaphor of the “swinging pendulum” to describe concerns related to policy. One participant expressed it this way:

It has a, just because it has become such a national issue and, and, and you know that it's being tracked, you know, that it's being monitored. And so sometimes that has become a determining factor for people within the field of hospice and palliative care. And what are the end outcomes of that? Do you think it becomes harder to do, to do the right thing if a, uh, you know, this is a gonna have such unwarranted focus and attention?

Discussion

This study focused on clinician's perceptions of the impact of the opioid epidemic on hospice and palliative care. All participants in this study had seen an impact on their patients due to the opioid epidemic, although, hospice seemed less affected than palliative care. Most participants seemed to value the use of opioids for managing distressing symptoms in patients with complex and life-limiting illnesses. Despite being regulatorily excluded from many of the provisions outlined in the CDC guidelines and NC STOP Act, participants in this study describe unintended consequences resulting from the shift in the medical culture away from opioid prescribing. It is clear that these study participants do not view hospice and palliative care as working in a disciplinary silo, insulated from the forces affecting the outside medical community. As primary care providers, oncologists, and other medical clinicians grow increasingly reluctant to prescribe opioids, it has a ripple effect reaching those vulnerable patients with life limiting illnesses. Participants voiced that these changes led to limited access to opioids, poor pain control, and patient suffering.

All study participants identified organizational and structural concerns due to the opioid epidemic that impacted their practices. Problems involved lack of resources, perception of increased risk among other clinicians, and a lack of leadership support. Of

the various barriers to opioid prescribing identified in this study, factors at the organizational level might be those that are best suited to intervention. Implementation of prescribing protocols using opioid risk assessment tools, drug monitoring programs, and pain contracts can be implemented in hospice and palliative care to help ensure safe prescribing. Education and training can be performed with clinician staff to ensure that they understand policy and the role of opioids in managing distressing symptoms for patients nearing end of life. Additionally, educational strategies can be employed with department leaders to ensure that they are able to nimbly react to the changing opioid landscape and support their clinicians in providing evidence-based treatment.

Regulators should understand the broad impact of opioid policies even in the setting of specialty exclusions. Several participants voiced concern that future policies could more directly target patients in hospice and palliative care. One participant felt that palliative care was particularly vulnerable to oversight given the broad nature in which some health care organizations define the scope of the specialty. However, it seems imperative upon leaders within the specialty to advocate and lobby for reasonable and safe opioid prescribing policies that mitigate the potential unintended consequences of further limiting patient access to these medications.

More research is needed to further characterize clinician's perspectives and determine the impact of the opioid epidemic and related policies on hospice and palliative care patients. The qualitative design and localized sampling used in this study might limit transferability. A future study might nationally survey hospice and palliative care clinicians to gain a wider perspective on the potential impact of the opioid phenomenon.

Table 4.1 Study Participant's Characteristics (N = 10)

Characteristics	Total
Age Category (%)	
31-40	20%
41-50	30%
51-60	30%
61-70	20%
Female (%)	70%
Provider Type (%)	
Physician (MD)	60%
Nurse Practitioner (NP)	40%
Mean Number of Years as NP/MD	15.5
Mean Number of Years of Practice in Hospice/Palliative Care	6.7
Type of Practice (%)	
Inpatient Palliative Care	40%
Outpatient Palliative Care	30%
Hospice	30%

Table 4.2 Study Findings (N = 10)

Categories	Subcategories	Participants Mentioning (%)
Impact on the Patient	Undertreatment: Poor Pain Control/Limited Access to Opioids	100%
	Stigma/Victimization	50%
	Illicit Use	60%
	Fear	40%
Impact on the Clinician	Limited Changes Made to Individual Prescribing	60%
	Careful Prescribing/Use of Prescribing Protocols	50%
Impact on Nursing	Inappropriate Nursing Practices	60%
	Nurses as Patient Advocates	60%
Impact on the Specialty	Limited Impact Within Hospice	60%
	Organizational Problems: Leadership/Resources/Other Specialties	100%
	Determination of Patient Appropriateness/Referrals	60%
	Regulatory Influence: Protections vs Pressures	80%

CHAPTER V

DISCUSSION

Introduction

The purpose of this study was to descriptively examine the opioid prescribing practices among hospice and palliative care clinicians as these practices relate to the opioid epidemic and associated policies. This research used a qualitative descriptive design. Ten participants, who represented three different hospice and palliative care organizations within central North Carolina were interviewed using an open ended, semi-structured approach. Analysis of the data revealed four primary categories: (1) Impact on the Patient; (2) Impact on the Clinician; (3) Impact on Nursing; (4) Impact on the Specialty. These categories were subcategorized into 12 areas that descriptively characterized the participants' narratives. Many of the subcategories were interrelated. For example, "undertreatment" was particularly impactful to the patient and it was in part perceived to be affected by subcategories that were impactful to the clinician, nursing, and/or specialty (e.g. "Limited Changes Made to Individual Prescribing," "Inappropriate Nursing Practices," and/or "Regulatory Influence"). This chapter will explore the significant findings from the study as they relate to the previous literature, hospice and palliative care, nursing practice, education, theory, policy, and future research. Study limitations will also be discussed.

Significant Study Findings

Impact on the Patient

All participants in this study perceived patients as having been impacted by the opioid epidemic and/or related policies. The category of “Impact on the Patient” was subcategorized into areas that highlighted the nature of that impact. Subcategories consisted of “Undertreatment: Poor Pain Control/Limited Access to Opioids,” “Stigma/Victimization,” “Illicit Use,” and “Fear.”

Undertreatment: Poor pain control/limited access to opioids. Universally, participants voiced having experienced patients with undertreatment from either limited access to opioids or poor pain control. This experience is perhaps best illustrated through the following quote by a participant:

We have, uh, seen at least one or two...Tylenol overdoses because, uh, these severe cancer pain patients had no access to, um, safely getting the right type of medications that they need. So they just took as much as they needed of whatever they could get their hands on. So GI bleeds from excess NSAID use is getting common, Tylenol overdoses are getting common. And then the stigma on top of all of this that now they're labeled, uh, you know, overdose patients, and now they have a psych consult to help determine capacity and, you know, how, how much below dignity can, can these people, you know, go, uh, as they're battling, uh, you know, serious life limiting illness. That's what's at stake here.

The implications of this statement are profound. The participant clearly characterizes harm befalling patients due to limited access from opioids in patients managed under an inpatient palliative care model. The existing literature provides limited data upon which to compare these findings. However, there does exist data that supports the

undertreatment of pain specifically in cancer patients (Fisch et al., 2012; Haider et al., 2017; Kirou-Mauro et al., 2009).

Limited access to opioids or reduced opioid dosing in patients with severe cancer pain syndromes would suggest undertreatment. It is not reasonable to generalize the above participant's experience of acetaminophen overdose with a phenomenon that extends outside the hospital and region in which the clinician practices. However, these findings are particularly disturbing considering the existing guidelines that support the use of opioids in managing oncologic pain (P. J. Wiffen, Wee, Derry, Bell, & Moore, 2017). Opioids remain the centerpiece of the World Health Organization's pain ladder and are recommended for mild, moderate, and severe pain with the goal of achieving freedom from cancer pain (World Health Organization, n.d.-b).

Stigma/victimization. The subcategory of "Stigma/Victimization" describes participants' perceptions that other members of the healthcare team have implicit biases, stigma, or have engaged in labeling of patients due to the opioid epidemic. This subcategory also reflects the view of a minority of participants, that patients are being directly victimized as a result of the opioid epidemic or changing policies. Although, just a few participants detailed experiences of victimization, the phenomenon seemed particularly impactful to the patient experience. This is perhaps best described by the following quote from a participant:

These patients can become victims as well, you know? Um, especially when you decrease the supply on the outside, like when patients can't, you know, chronic pain patients, even substance abuse patients can't get what they need, treatment

for their addiction. I mean, sometimes these patients can even become targets, like victims, so people will steal their meds or replace her meds.

Participants seemed especially keen to identify stigma when a patient

unintentionally overdosed on an opioid or was identified by the healthcare team as being “drug seeking.” Participants stated that these biases among the healthcare team led to an unwillingness among clinicians to prescribe or administer opioids. One participant described labeling in this way, “It’s stigma is what it is. The drug seeker is inherently a bad patient...it's not a medical term and we should stop using it.” Stigma as it relates to opioid prescribing and patients with a history of addiction has been well documented in the literature (Buchman, Leece, & Orkin, 2017; Bulls et al., 2019).

Illicit use. The subcategory of “Illicit Use” was described as a concern for a majority of the study participants. Some study participants identified having experienced patients with addiction and abuse of opioids. However, a majority of participants seemed to perceive illicit use as a byproduct of undertreatment of pain or limited access to opioids due to the opioid epidemic, changing policies, and restricted prescribing by other clinicians. The phenomenon of illicit use was perhaps best described by the following participant:

We also have people who are using illicit drugs to control their pain because they can't get, uh, drugs in legal ways. They're taking it out of their relative's closet or they're having unusual urine drug screens because they're so desperate for this relief.

Another participant described it in this way:

People will become drug addicts. People will shoot themselves. I mean, you know, if you've got incredible pain, you're gonna find a way to get out of pain and it's gonna be, you know, heroin or suicide or something. And to me, that's not justifiable.

Concerns regarding the illicit use of opioids by patients have been identified in studies examining clinician prescribing (Franklin et al., 2013; Kennedy-Hendricks, Richey, et al., 2016; Knight et al., 2017). However, these studies involved specialties outside of hospice and palliative care. Additionally, the clinicians in these studies characterized illicit use as a barrier to their individual prescribing and seemed to view their patients through a critical lens. Contrary to this perspective, the participants in this study viewed illicit use of opioids as a phenomenon that occurred in part due to prescribers' unwillingness to treat pain with opioids. Clinicians stated that they were concerned that undertreatment would increase the prevalence of addiction and illicit opioid use. One participant characterized her fears by stating:

So, my concern is it's a true pain. They've had it for a while, that they're not going to get [opioids]. It'll just [boom] you'll get cut off. And could that drive you to, could that drive you to buy something from another source, get a product off the street, relapse on alcohol? I mean, unmanaged pain drives people to, to, to places they never thought they would be. That's my, my biggest fear now.

Fear. The subcategory of “Fear” describes clinician perception that patients or families have heightened concerns related to opioid prescribing due to the opioid epidemic and/or policies. Fear and concerns among patients and caregivers has

previously been documented as a barrier leading to undertreatment of symptoms (Chi, Demiris, Pike, Washington, & Oliver, 2018). However, this previous study did not explore if patient and caregiver fears were exacerbated by the opioid epidemic.

Primarily, study participants identified media sources as being influential in increasing patient fear of opioids. Participants verbalized patient or family fear as a barrier to their prescribing opioids in some cases. This fear could impact patients by leading to undertreatment of pain and other distressing symptoms. One participant described it in this way:

So, it's been this flip culture too, unexpected, unintended consequences where patients are saying, I don't want to be addicted. That's a hard one. Or family say don't give them that, you know, because they've heard, you know, how horrible Oxycontin is on TV.

Another participant characterized patient and family concerns in the hospice setting:

The people are all exposed, some of them, like us, have heard, over and over the crisis in the nation about opioid addiction, opioid deaths. So obviously as I said before, even sometimes when I think maybe we could try some opioids, there may be some barriers into utilizing them when I think perhaps could be useful. And again, I'm saying perhaps, um, fears of addiction, fears of uh, hastening death.

Impact on the Clinician

The category of “Impact on the Clinician” describes the participant’s perceptions of how the opioid epidemic and related policies have directly impacted their own opioid prescribing. This category was further divided into two subcategories, including “Limited Changes Made to Individual Prescribing” and “Careful Prescribing/Use of Prescribing

Protocols”. As this is the first known study to qualitatively describe the perceptions of hospice and palliative care clinicians related to the opioid epidemic, there does not exist a body of literature with which to directly compare the significance of the study findings.

Limited changes made to individual prescribing. A majority of the study participants indicated that they felt they had not changed their own opioid prescribing practices due to the opioid epidemic and policies. One participant had this to say about the opioid epidemic:

I really don't look at it as a barrier. I mean there's a place for [opioids], if it's indicated, its needed, I write it. I don't worry about, no, I don't worry about an epidemic and don't worry about any of that stuff because then you're going to maybe not give it to someone who needs it.

Participants universally spoke of how the unwillingness of other clinicians to prescribe opioids would impact their patients. Some participants discussed feeling insulated within hospice and palliative care and therefore did not feel a need to change their own prescribing. Some also spoke of the unknown of practicing in other specialties and that they thought it possible that they too would be influenced by the same factors limiting opioid prescribing if they were practicing in primary care or another medical specialty. Comparatively, the existing literature suggests that many clinicians practicing in specialties other than hospice and palliative care perceive that they have changed their opioid prescribing practices related to the opioid epidemic and/or related policies (Franklin et al., 2013; Jamison et al., 2014). It is also noteworthy that there is evidence that self-perception of prescribing practices can be inaccurate (Michael et al., 2018).

Careful prescribing/use of prescribing protocols. Although a majority of study participants did not perceive that their own prescribing practices had changed as a result of the opioid epidemic, half described the importance of careful prescribing and/or the need to use prescribing protocols in hospice and palliative care. Participants suggested use of prescription drug monitoring programs (PDMP), risk assessment tools, pain contracts, and ongoing monitoring using pill counts and urine drug screens. Despite many participants suggesting that prescribing protocols should be in place, it is not clear how often these practices occur. One study found that screening policies and risk mitigation strategies were rarely practiced in a palliative care clinic (Tan et al., 2015). A participant in this study described their clinical approach for opioid prescribing in inpatient palliative care this way:

So I think through continued research and using very reasonable, in my mind, approaches to risk stratifying things like an opioid risk tool prior to prescribing medications, using things like a urine drug screen, uh, for followup of those, you know, um, concerns about misuse, looking at the, the prescription monitoring programs before any scripts are given. Um, simple safety things like assessing who's in the home. Um, what is the past history of substance use either for the individual or family members.

Impact on Nursing

Study participants often discussed the role of nursing in facilitating or acting as a barrier to effective pain management in hospice and palliative care. Collectively, these perspectives describe the influence of the opioid epidemic and related policies on nursing. The category of “Impact on Nursing” was divided into two prevalent

perspectives forming the subcategories of “Inappropriate Nursing Practices” and “Nurses as Patient Advocates.”

Inappropriate nursing practices. Inappropriate nursing practices were identified universally among those clinicians who work in inpatient settings. Primarily, clinicians described nurses as being fearful of opioids and therefore reluctant to administer as needed doses when patient were symptomatic. This resulted in a change in clinician’s management of pain and often required scheduling of the medication. One participant described it in the following way:

I think that part of the, the cultural shift is coming particularly with newer nurses, is like a phobia of giving people even appropriate doses of pain medications, um, because of their perceived, you know, possible bad side effects of it...I'm more seeing patients who have ordered as needed medications, not getting them at the point that I feel would probably be the point that I would administer that medication. There's a lot of clinical judgment that goes into that. I think that's why it's still important to continue to, to educate providers that are at the bedside.

Participants also commonly identified a perception that staff nurses lacked appropriate education and training in opioid management and that this knowledge deficit led to inappropriate medication administration. Another participant stated:

I'm not getting any PRNs given and I'm walking in seeing somebody breathing 40 times a minute. I'm seeing a real lack of education no matter how many times I stress opioids are not just for pain. This is for this dyspnea. It's written on the orders to give on either, but I'm not getting them given

Participants also suggested that issues with administration of as needed medications seemed to vary based on the level of nursing experience or the nursing unit. Both attitude

and unit location have been shown to affect the willingness of the nurse to administer as needed medication (Youngcharoen, Vincent, & Park, 2017). Research has also shown that nurses can fear hastening death in patients that might be nearing end of life in the acute care setting (Howes, 2015).

Nurses as patient advocates. In a 2018 position statement, The American Nurses Association reaffirmed the need for nursing advocacy in ensuring that patients receive appropriate pain management to avoid suffering (American Nurses Association, 2018a). A majority of participants in this study described the role of nurses as advocating for appropriate pain management. This advocacy was recognized even by participants who also described problems with some nurses adhering to the plan of care when administering as needed medications. However, nurses as patient advocates seemed to be a more prominent description from participants who worked in community palliative care and hospice. One participant, a hospice physician, spoke of the role of nurses as advocates and how they perceived those nurses to feel when they encountered barriers to proper pain control:

They look at someone and they say, this person's in pain or this person, you know, needs something. And they're told, you know, no they're not. I mean, that denigrates their profession to, be able to, to have to hear that. And you know what they all say is they get these 20-minute lectures about, you know, what you think is pain is not really pain. And so, then that ends up affecting their workday as well. And I think sometimes they don't want to call people because they're afraid they're going to get this lecture.

Another participant also spoke of how they perceived nurses to feel when those nurses were unable to obtain proper pain relief for their patients:

It's very distressing for the nurses when people can't get medicine that they think that they should get. Um, and you know, and I think that they're willing to try alternatives and do whatever. But I do think, um, they feel, they feel that they're the patient advocates.

Impact on the Specialty

Study participants universally described the opioid epidemic and related policies as having an impact on hospice and palliative care. However, the characterization of this impact varied based on the practice setting and type of clinician (hospice vs palliative care). The impact on the specialty was further categorized into four subcategories including: “Limited Impact Within Hospice,” “Organizational Problems: Leadership/Resources/Other Specialties,” “Determination of Patient Appropriateness/Referrals, and “Regulatory Influence: Protections versus Pressures.”

Limited impact within hospice. Most study participants felt that hospice had been relatively sheltered from the impact of the opioid epidemic and related policies, at least compared to other medical specialties. Participants widely reported using opioids within hospice to manage patients’ end of life symptoms. One of the participants in this study held a leadership position within a hospice organization and did suggest a view that opioids were over prescribed within hospice and that symptoms near end of life might be a normal physiological process with limited evidence to support the use of opioids to ameliorate distress. However, these views did not seem reflective of the majority of participants in this study. This participant also described an internal audit that found nearly 100% of patients within their hospice had access to opioids. This finding mirrors research that suggests that use of opioids is prevalent within the hospice setting

(Borgsteede et al., 2009; Childers et al., 2015; Heneka et al., 2018). One participant described use of opioids in hospice in the following way, “People who go into hospice feel that end of life needs to be comfortable, whatever that takes and that it often requires opioids. So, I do think that opioids are prescribed. I just, I don't think it's changed.”

Participants suggested that opioids were culturally part of hospice care and that had not changed due to pressures from the opioid epidemic. One participant phrased it this way:

And to some degree, uh, if you were to look into our population, 100% of our patients get an opioid, even if there's no, perhaps evidence that there was a need for it. So that cultural ingrained that opioids, uh, was a vehicle that was safe, necessary and pain was a real objective and manageable problem, which we call the fifth vital signs, that also was part of the hospice culture.

However, another hospice physician interviewed felt that there had been some increased scrutiny resulting from the opioid epidemic but that the impact had been minimal. They described it in the following way:

Obviously, the opiate epidemic is not meant for [hospice], but we do feel the ramifications of it cause we just can't hilly nilly write buckets full of medications. It still has to be indications to us to say, this is the plan. Is it working? Are they following it? And also when we, even in our own roles, we have tightened it. Uh, but we're not, we're not, not giving it because we worry about an epidemic.

Some clinicians working in the hospice setting described an organizational policy where they were encouraged to have the clinician referring a patient to hospice (i.e. primary care) continue prescribing opioids while the patient was enrolled in hospice services. Hospice clinicians described receiving “push back” from the referring clinicians

who wanted them to take over opioid prescribing. One participant described it in the following way:

I mean just a number of times that suddenly the primary care person would say, oh they're hospice now. I'm not prescribing it now... I can refer to another hospice and, and they'll write these medicines. Why don't you write the medication? So that's the other thing that makes me think that it was a little bit organizational. And again, the piece I don't understand, is it organizational from high administration or is it coming from the supervisor?

Limited impact within hospice: Barriers. Universally, study participants felt that organizational problems caused barriers to opioid prescribing within hospice and palliative care. The most common barriers described were a lack support among leadership, limited resources, and problems among other specialties that impacted hospice and palliative care patients. Although most clinicians felt that hospice as a specialty had limited impact due to the opioid epidemic, a few clinicians identified significant problems within their hospice workplace. These problems appeared to be associated with lack of leadership support or an organizational culture that did not facilitate opioid prescribing. It is unclear if these problems reflect a broader shift in hospice prescribing culture or if they were just associated with the hospice organizations used in this study. Previous research has shown that prescribing culture and training background can be perceived as influential in opioid prescribing practices (Pomerleau, Schragger, & Morgan, 2016).

One physician described being told by her supervisor that she could not prescribe to a particular patient despite feeling like it was clinically prudent. She appeared to have some moral distress related to this problem and described it in the following way:

So, the attending wouldn't prescribe [opioids] and [my supervisor] said, you cannot prescribe this. You know, he flat out said you can't do it, period. Amen. So, the man never got any more of that and we ended up doing a lot of Ativan, things like that, but really nothing ever worked. And then at the very end, I did end up giving him some Roxanol... I was flat out told by my boss, you cannot do this. I'm telling you you can't do this. And I even said to him, you're telling me how to practice medicine? And he said, well, in this case I am.

All the participants of this study universally identified problems that arose from the involvement of clinicians in other medical specialties and the general reluctance of these clinicians to prescribe opioids. This finding alone perhaps highlights the interconnectedness of hospice and palliative care patients and clinicians to the complex nature of the healthcare system. Hospice and palliative care patients are not fully insulated by the influential factors that affect opioid prescribing practices within the healthcare system at large. Although patient might be followed by hospice and palliative care clinicians, these patients still often rely on outside specialties for opioid prescribing. Primary care was commonly identified in this study as being a specialty where clinicians were particularly reluctant to engage in opioid prescribing. The literature suggests that primary care clinicians have concerns associated with prescribing opioids for chronic, non-cancer pain (Breuer et al., 2010; Franklin et al., 2013; Jamison et al., 2014; Knight et al., 2017).

One participant described it in this way, “We have difficulty getting providers in the community to even prescribe for them at all.” Other participants described oncologists as being reluctant to prescribe opioids:

People who have metastatic cancer related pain and, uh, there's nobody to write those medications for these patients. Um, a lot of times even the cancer centers are, um, referring these people to pain medicine specialists, uh, to go get their opioids from their primary care providers have just about stopped altogether and even oncologists have stopped.

Yet another participant had this to say about the reluctance among oncologists to prescribe opioids:

You have a partner entire health system who not a single oncologist in the practice will prescribe opioids. So, it all goes to palliative care. Every single opioid prescription that goes out at that cancer center is done by Palliative care.

Study participants who work in inpatient palliative care frequently identified problems with hospitalists and a general unease surrounding opioid prescribing. Palliative care clinicians are often consultants in the hospital and therefore the primary clinical decision making is the responsibility of the referring clinician, often the hospitalist. Study participants spoke of making recommendations regarding opioid prescribing that were not always agreed upon by other members of the medical team. Study participants also spoke of making changes to the opioid regimen in the hospital but not having the resources outside the hospital to facilitate post discharge pain management. One participant described it this way:

Like I can't get the hospitalists to continue the medicine, even if we get consulted for symptom management. So, say I go in there and I do make you better. Who's gonna pick it up from there? I can't get them into a pain clinic. If your primary care office isn't going to prescribe it because they're all, you know, imagining all this liability, you're not imagining them. Sure. But they're, you know, fearful of all this liability and addiction and problems and patients. Um, it's, it's, I, I think it's, it's a real problem.

Determination of patient appropriateness/referrals. Most study participants suggested that they had seen an influx in referrals due to the opioid epidemic. In the case of hospice, clinicians described receiving referrals earlier and with an expectation by the referring clinician that hospice would take over management of the opioids. Palliative care clinicians described receiving an increased number of referrals for pain management. These referrals were described as being difficult for clinicians working in community palliative care, as they did not assume the responsibility of prescribing opioids, which was often the nature of the referral. One nurse practitioner interviewed described it this way:

I think as a palliative provider, I think that, you know, the focus has shifted from one direction to the other, whether it's chronic disease management and preventing hospitalizations to symptom management and focus specifically on pain. Sometimes that's physician's easy, their easy way out of saying, okay, well we'll just get somebody to come to your house and talk to you about pain management and they can deal, you know, help you sort those things out, which is great. But you know, then the patients don't quite understand that you're not going to hand them a prescription.

Some participants identified the broad nature of palliative care as being potentially problematic to opioid prescribing. These participants questioned how to best determine the appropriateness for patients who would be followed by palliative care and

thus who would be regulatorily excluded from policies designed to curb opioid prescribing. Hospice clinicians did not seem to have this concern as hospice is better defined prognostically for patients limited to six months or fewer of life expectancy. One participant described it in the following way, “Where do you kind of draw them line and sort of what patients are palliative, which patients are really in more of a chronic pain management situation?” Another participant described this concern:

I mean there is good evidence, cancer related pain is well treated by opioids. There is not that same evidence to support a lot of these chronic pain things that these people have been on opioids. So just relabeling it as a palliative care and continue with a medication that's not been proven to be beneficial, I think will lead to more regulatory issues in the future.

Regulatory influence: Protections versus pressures. The literature overwhelmingly suggests that policies have been influential in reducing the number of opioids prescribed in outside specialties (Bao et al., 2016; Barbera, Sutradhar, Chu, Seow, Earle, et al., 2017; Bernhardt et al., 2017; Breuer et al., 2010; Click et al., 2018). However, there exists limited literature that specifically evaluates the impact of policy on hospice and palliative care. A majority of study participants described changes in policy related to the opioid epidemic as having an impact on the specialty of hospice and palliative care. The regulatory influence was characterized as either offering protection or creating pressures for opioid prescribing in the specialty of hospice and palliative care. One participant described the regulatory protections offered to hospice and palliative care in the following way, “The guidelines specifically exclude palliative care and they use the word palliative care. Um, so, um, I feel like I personally and professionally and protected

because I have a board certification in palliative care.” Another participant described the regulatory pressures from policy in the following way, “The STOP Act. Sounds pretty scary, doesn't it? Like the STOP Act, you know, stop prescribing is the message I get from that, but I'm not going to stop prescribing.” Yet another participant also described the impact of regulatory policy acting as a barrier to opioid prescribing in the specialty of palliative care.

People have posted on social media where in certain states, even hospice and palliative providers have received letters from Medicare or from CMS, uh, saying that, uh, their name has come up as one of the highest prescribers and, uh, informing them about the perils of the opioid crisis. And, uh, you know, they do, they haven't even looked that these are hospice and palliative providers. That's why they're writing for what they're writing. So they're getting official letters...it has, just because, it has become such a national issue and, and, and you know that it's being tracked, you know, that it's being monitored. And so sometimes that has become a determining factor for people within the field of hospice and palliative care. And what are the end outcomes of that? Do you think it becomes harder to do, to do the right thing if, uh, you know, this is a gonna have such unwarranted focus and attention?

Implications

This study aimed to describe the impact of the opioid epidemic and related policies on prescribing practices and end of life care in the setting of hospice and palliative care. The findings help fill an important gap in the existing literature. The implications of this study are potentially far reaching, affecting a variety of areas in clinical practice, education, theory, policy, and future research.

Hospice and Palliative Care

The findings of this study suggest that the opioid epidemic and related policies have had a substantial impact on patients, clinicians, and the specialty of hospice and palliative care. Hospice was described as being less impacted than palliative care. However, despite policy exclusions, this study suggests that there are still vulnerable patients with life limiting illnesses that are undertreated or have reduced access to opioids. All participants in this study seemed to recognize and value opioids as a tool instrumental in alleviating pain and suffering for those patients with severe or life limiting illnesses managed under hospice and/or palliative care.

This study provides evidence that hospice and palliative care exist within the broader medical community and are therefore impacted by any policy changes that affect these outside medical specialties. Palliative care clinicians interviewed for this study spoke of the referral and consulting nature of the specialty and a need for cooperation with other medical clinicians to ensure that patients had access to opioids. Clinicians working in the inpatient setting frequently relied on hospitalists to recognize the need for consultation of palliative care and to adhere to recommended changes in the opioid regimen. These inpatient palliative care clinicians also spoke of the difficulty in transitioning care after the patient discharged from the hospital. A lack of community resources for both inpatient and outpatient palliative care led to patients relying on primary care providers to assume responsibility for prescribing opioids. Unfortunately, all too often this reliance on outside specialties resulted in reports of undertreatment.

Particularly troubling is the reported trend by multiple study participants of a growing reluctance among oncologists to prescribe opioids. Oncology is a specialty that often results in palliative care referral (Courteau, Chaput, Musgrave, & Khadoury, 2018). One study participant spoke of an entire oncology group that no longer prescribed opioids as a policy and instead referred only to palliative care for opioid management. Other studies have also shown a trend of under prescribing among cancer related patients (Haider et al., 2017). Despite these changes, opioids remain a mainstay for the treatment of cancer pain (World Health Organization, n.d.-b). It is unclear what role palliative care might have in the future for the management of oncologic pain as the medical community continues to adapt to the opioid epidemic.

Study participants clearly perceive opioids as an important tool in the armamentarium needed to combat distressing symptoms in patients with life-limiting conditions. It is important that clinicians working in the specialty advocate for patients to receive these medications, if there is clinical indication and the ability to safely prescribe. Hospice and palliative care clinicians can also use their expertise to help ease the concerns of clinicians in outside specialties that might be fearful to prescribe opioids. It appears that the specialty of hospice and palliative care will continue to have an important role in the utilization of opioids for vulnerable patients. This study identified several gaps in existing community resources that should be addressed. The development of future community hospice and palliative care programs should consider the problem of opioid access and how the specialty can facilitate prescribing to those patients most in need.

Nursing Practice

This study highlights the involvement of nurses in pain management in both hospice and palliative care. The study findings suggest that nurses maintain a strong sense of advocacy in helping facilitate opioid prescribing for patients enrolled in hospice. This advocacy is aligned with the interdisciplinary role encouraged by the American Nurses Association in the era of the opioid epidemic (American Nurses Association, 2018a, 2018b). Participants spoke of hospice as being rooted in a historical culture that empowered nurses to help shape the pain management needs of patients. One physician discussed acquiescing to the requests of the nurse for opioids in an attempt to be perceived as the “good hospice doctor” even if he did not feel opioids were clinically indicated. However, other participants described the perceived moral distress that nurses encounter when they face barriers in obtaining opioids for symptomatic patients at end of life. These nurses seemed duty bound to obtain relief for patients despite facing clinicians who were reluctant to prescribe opioids. Describing how nurses navigate and respond to these challenging inquiries was not an aim of this study. However, nurses’ perceptions should be explored in future research given the importance of the role in helping to shape the pain management plan in the hospice setting.

This study also revealed concerns, primarily among inpatient palliative care clinicians, of nurses engaging in inappropriate practices surrounding the administration of opioids. Nurses were described as often being reluctant to administer as needed opioids for patients with distressing symptoms. Clinicians perceived nurses as being fearful of the effects of opioids. Biases and stigma were also mentioned as possible factors leading to

inappropriate nursing practices. Clinicians described the need to adjust their prescribing due to nurses failing to appropriately administer ordered opioids. The observations of nursing practices in the hospital seem contrary to the advocacy reported by nurses in the community. These experiences are curious and likely speaks to organizational and cultural differences between the practice settings. However, given that nurses were not interviewed in this study, not enough data exists to fully describe their role in this phenomenon.

Nursing Education

Several of the participants in this study perceived nursing and medical staff as needing additional education regarding opioid prescribing and appropriate administration. Participants related feeling that nurses in particular were fearful of opioids and that education might improve their confidence, eliminating a barrier to treatment. Similarly, participants implied that physicians in outside medical specialties were over emphasizing the risks associated with prescribing and that this fear might come in part due to how these clinicians were trained.

Professional education has been a strategy used to respond to the opioid epidemic. The National Academy of Medicine and partner organizations have called to expand training in medical schools on opioid prescribing and techniques to respond to the opioid epidemic (National Academy of Medicine, n.d.). Similarly, the American Association of Colleges of Nursing (AACN) has set a goal to train 15,000 nursing students and faculty on opioid prescribing practices and bring awareness to more than 60,000 stakeholders regarding the opioid epidemic. Through this call to action, 44% of nursing schools in

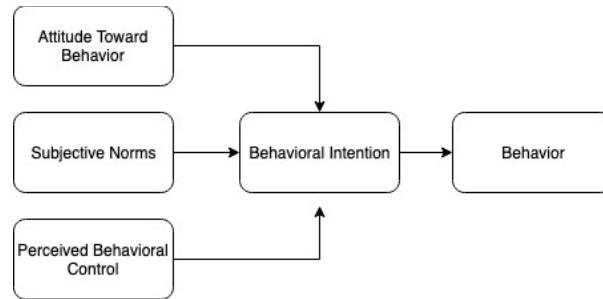
North Carolina have pledged to teach the Centers for Disease Control and Prevention (CDC) guidelines related to opioid prescribing (American Association of Colleges of Nursing, n.d.). The expansion of professional education in response to a national epidemic is laudable. However, the context of this education has potential to shape clinical practice among future and current clinicians. It is unclear if these schools of nursing and medicine will emphasize the exclusions found in the CDC guidelines for opioid prescribing within hospice and palliative care.

The AACN has also recommended increased training in palliative care for nursing students (Zolot, 2016). Historically, palliative care was not emphasized within the training curricula for nurses and other health professions (Wee & Hughes, 2007). Additionally, many nurses report a lack of confidence and training in hospice and end of life care (Bassah, Seymour, & Cox, 2014). How schools of nursing and medicine deliver palliative care content, particularly as it relates to the opioid epidemic should matter greatly in the confidence of these clinicians when they enter practice.

Education should continue to play an important role in addressing the opioid crisis. However, educators need to ensure that content is grounded in evidence and not delivered in a way that creates fear or bias in those tasked with prescribing opioids. As was suggested by study participants, training should ensure that clinicians feel comfortable treating pain and are able utilize opioids in a safe and efficacious manner.

Theory

Figure 5.1 The Theory of Planned Behavior (Ajzen, 1991)



This study used the Theory of Planned Behavior (TPB) as a guiding framework and for creation of the interview guide. The TPB has been shown to be useful in predicting those factors that are influential to behavior such as prescribing medications (Ali Murshid & Mohaidin, 2017). The constructs of the TPB (attitude, subjective norms, and behavioral control) influence intentionality making behavior more or less likely to occur (Ajzen, 1985, 1991; Montano & Kasprzyk, 2015).

The findings of this study are theoretically congruent with the TPB as a predictive model of prescribing behavior. The study reveals a variety of factors that participants felt would either increase or decrease the prescribing of opioids in hospice and palliative care. Patient enrollment in hospice, nursing advocacy, and policies that insulated the clinician from regulatory scrutiny were all described as facilitating opioid prescribing. Factors that were described as barriers to opioid prescribing included workplace culture, stigma, fear, lack of community resources, lack of leadership support, an organizational structure that prohibits prescribing, and policies that were overly restrictive.

The study findings can be categorized by related TPB constructs. For example, most of the participants' perceptions regarding patient impact (e.g. undertreatment, stigma, illicit use, and fear) involve the evaluation and beliefs of behavioral outcomes (i.e. opioid prescribing), which would align with the TPB construct of "Attitude." The impact on the clinician would align with the constructs of "Behavioral Intention" and "Perceived Behavioral Control." Participants generally described feeling that they had not, nor would they change their prescribing practices due to the opioid epidemic or related policies. This belief involves "Behavioral Intention" to continue prescribing opioids within hospice and palliative care. Participants also described use of prescribing protocols and careful prescribing as a way that the opioid epidemic had impacted the clinician. Use of prescribing protocols align with the TPB construct of "Perceived Behavioral Control" or those factors that affect a participants' perception of facilitating or impeding the behavior (Ajzen, 1985, 1991; Montano & Kasprzyk, 2015).

The impact on nursing was subcategorized into "Inappropriate Nursing Practices" and "Nurses as Patient Advocates." Both of these subcategories seem to align with the TPB construct of "Subjective Norms." Subjective norms are the beliefs and perceptions of how others view the behavior. Participants seemed to categorize nurses in a dichotomous fashion as either being fearful of opioids or strongly advocating for their use.

The impact on the specialty involved subcategories that could be classified into all three main antecedent constructs of the TPB (Attitude, Subjective Norms, and Behavioral Control). The perception of "Limited Impact Within Hospice" from the opioid epidemic

is both an evaluation of outcomes (Attitude) and also describes the social norms (Subjective Norms) among peers within the hospice specialty. Similarly, “Organizational Problems” reflects both the “Subjective Norms” of peers, leadership, and organizational culture. “Organizational Problems” also involves “Perceived Behavioral Control” as participants identified many barriers such as lack of resources and problems with other specialties that affect the perceived power of the clinician to prescribe opioids. The subcategory of “Determination of Patient Appropriateness/Referrals” involves the study participants’ evaluation of the outcomes (TPB construct of Attitude) inherent from the problem and behavior. Finally, the subcategory of “Regulatory Influence” is most closely aligned with the TPB construct of “Perceived Behavioral Control” as it involves regulatory factors that are perceived to either insulate the prescriber within the specialty or provide pressures to reduce opioid prescribing.

Table 5.1 Relation of Major Study Findings to Theoretical Constructs

Categories	Subcategories	Theory of Planned Behavior Constructs
Impact on the Patient	Undertreatment: Poor pain control/Limited access to opioids	Evaluation of Outcomes (Attitude)
	Stigma/victimization	Belief about Outcomes (Attitude)
	Illicit use	Belief about Outcomes (Attitude)
	Fear	Belief about Outcomes (Attitude)
Impact on the Clinician	Limited changes made to individual prescribing	Behavioral Intention
	Careful prescribing/Use of prescribing protocols	Perceived Behavioral Control
Impact on Nursing	Inappropriate nursing practices	Subjective Norms
	Nurses as patient advocates	Subjective Norms
Impact on the Specialty	Limited impact within hospice	Subjective Norms AND Evaluation of Outcomes (Attitude)
	Organizational Problems: Leadership/Resources/Other Specialties	Perceived Power (Perceived Behavioral Control) AND Subjective Norms
	Determination of patient appropriateness/referrals	Belief about Outcomes (Attitude)
	Regulatory Influence: protections vs pressures	Perceived Power (Perceived Behavioral Control)

Policy

Study participants described policy as being either restrictive or protective given the nature of the clinical practice specialty. Most participants cited hospice and palliative care as being specifically excluded from opioid prescribing restrictions in the CDC guidelines and the North Carolina Strengthen Opioid Misuse Prevention (NC STOP) Act of 2017. Given these exclusions, participants felt that they generally had limited individual risk prescribing opioids. However, some participants identified the broad way in which palliative care can encompass patients across an illness continuum, as being potentially problematic in how the specialty is excluded from regulatory restrictions. Guidelines frequently recommend palliative care consultation early in the course of an illness, while a patient still plans to pursue curative therapy (Courteau et al., 2018). Given the broad scope of palliative care, study findings suggest that these patients are more likely to encounter outside medical specialties that are involved in opioid prescribing. It appears to be these outside specialties that are at most risk of undertreatment, given the regulatory pressures applied through policy. This finding is mirrored in the literature that suggest restrictive policies can decrease opioid prescribing (Baehren et al., 2010; Bao et al., 2016; Gomes et al., 2014).

This study suggested that policy exclusions for hospice and palliative care were an important factor in ensuring that clinicians within the specialty felt comfortable prescribing opioids. Although palliative care can be broadly defined, it is important that the specialty continue to receive regulatory exemption from the restrictions commonly found in policies designed to curb opioid prescribing. Specialty organizations such as the

National Hospice and Palliative Care Organization (NHPCO), Center to Advance Palliative Care (CAPC), American Academy of Hospice and Palliative Medicine (AAHPM), and the Hospice and Palliative Nurses Association (HPNA) all should continue to support lobbying, education, and research to advance policies that protect vulnerable patients within hospice and palliative care.

Study Limitations and Future Research

There are several important limitations to this study. First, this study used a sample in Central North Carolina. Although three different hospice and palliative care organizations were represented, it is unclear if the study findings reflect the perceptions of hospice and palliative care clinicians employed in other organizations or other geographical regions in the state and country. Future research should aim to address this by reproducing the study using a sample from a broader geographical area (i.e. multiple states). Additionally, a mixed methods study using survey design would allow for quantitative exploration of the phenomenon, while still retaining the rich contextual data offered through qualitative methods. Survey design would also provide a means through which to determine if the opioid epidemic and related policies are perceived by a national sample to be affecting opioid prescribing within hospice and palliative care.

Hospice and palliative care are inherently interdisciplinary. The findings in this study support the interconnectedness of hospice and palliative care to other members of the healthcare team. Study participants spoke of the role of nurses in facilitating or impeding the access of opioids for vulnerable patients. However, staff nurses were not a primary focus of this study. Future research would benefit from inclusion of nurses and

other interdisciplinary team members to help elucidate what impact the opioid epidemic is having on their roles as they care for hospice and palliative care patients. Additionally, future research might also include the perspective of hospice and palliative care patients as they navigate through a healthcare system that has increasingly limited access to opioids. The perspective of patients and their caregivers would provide invaluable insight into the true impact that the opioid epidemic and related policies are having on their symptom management and quality of life.

As with all qualitative research, the potential for bias may limit the creditability and trustworthiness of the data. In the case of this study, an effort was taken to limit bias through self-reflection, auditing, memoing, and use of faculty for review. Authenticity of the data was maintained through purposeful, flexible sampling and a focus on the richness of the data through the analysis process. Additionally, authenticity was facilitated through content analysis and use of *in vivo* coding, which helps ensure that study participants' perceptions are accurately represented (Neergaard et al., 2009; Saldaña, 2016).

As a method, qualitative description has a notable limitation given its usual lack of a theoretical framework and limited use of inference in the analysis process (Neergaard et al., 2009; Sandelowski, 2000). These factors are typically limited or absent given the descriptive nature of the research method. For this study, a theory was used to provide a contextual framework from which to develop the interview guide and interpret the findings. The Theory of Planned Behavior is well suited to help understand how and

why factors can lead to a change in the prescribing of opioids in hospice, palliative care, and related medical specialties.

Conclusion

This is the first known study using qualitative description to explore the impact of the opioid epidemic and related policies on opioid prescribing in hospice and palliative care. This study suggests that the opioid epidemic and related policies have had an unintended impact affecting patients, clinicians, nursing, and the specialty of hospice and palliative care. Although participants perceived hospice as being less impacted than palliative care, all participants spoke of unintended consequences leading to the undertreatment of patients.

This study found that generally there was a perception that hospice had been less affected by the opioid epidemic and related policies than palliative care. Participants that spoke of undertreatment or limited access within hospice generally described a lack of support among leadership and workplace culture as primary causative factors. However, all participants agreed that opioids were necessary within hospice to manage symptoms at end of life. These findings are consistent with prior research suggesting that opioids are still widely used within hospice (Borgsteede et al., 2009; Childers et al., 2015; Hanlon et al., 2010; Heneka et al., 2018; Hunnicutt et al., 2017).

This study suggests that despite regulatory protections for palliative care, patients are experiencing unintended consequences of policy as clinicians become increasingly hesitant to prescribe opioids. This problem appears compounded by the broad nature in which palliative care can apply to patients across a disease trajectory. Palliative care

patients often rely on clinicians in other specialties for pain and symptom management and are therefore vulnerable to a shift in the broader medical community as opioid prescribing becomes less frequent. Perhaps most troublesome, is the consistent report among many of the study participants that oncology patients have had increasing difficulty accessing opioids to manage their symptoms. The quality of evidence is strongest to support use of opioids for cancer related pain and symptoms at end of life (Lorenz et al., 2008). However, other research also finds a growing trend of reduced opioid prescribing and undertreatment of pain among oncology patients (Barbera, Sutradhar, Chu, Seow, Earle, et al., 2017; Fisch et al., 2012; Haider et al., 2017; Kirou-Mauro et al., 2009; Shaheen et al., 2010).

This study helps address an important gap in the literature by describing the hospice and palliative care clinicians' perceptions of how the opioid epidemic and related policies are influencing opioid prescribing within the specialty. Although this study suggests an impact leading to limited access of opioids, increased stigma, and fear among some clinicians, the barriers to prescribing opioids were primarily perceived as involving related medical specialties. More research is needed to explore this phenomenon. Although policy is necessary to respond to the large scope of the opioid epidemic, policy makers should be cognizant of the potential for unintended consequences affecting vulnerable patients with life limiting illnesses. Opioids seem likely to remain a mainstay for the management of symptoms in hospice and palliative care. However, as the broader medical community shifts away from opioid prescribing, care must be taken to ensure that hospice and palliative care patients still receive access to needed medications. The

relief of human suffering at end of life must be prioritized in the development of future health policy and research.

REFERENCES

- Ahrnsbrak, R. (2016). Key substance use and mental health indicators in the United States: Results from the 2016 National Survey on Drug Use and Health. Retrieved from <https://www.samhsa.gov/data/sites/default/files/NSDUH-FFR1-2016/NSDUH-FFR1-2016.pdf>
- Ajzen, I. (1985). From intentions to actions: A theory of planned behavior. In J. Kuhl & J. Beckmann (Eds.), *Action control: From cognition to behavior* (pp. 11–39). https://doi.org/10.1007/978-3-642-69746-3_2
- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, 50(2), 179–211. [https://doi.org/10.1016/0749-5978\(91\)90020-T](https://doi.org/10.1016/0749-5978(91)90020-T)
- Ali Murshid, M., & Mohaidin, Z. (2017). Models and theories of prescribing decisions: A review and suggested a new model. *Pharmacy Practice*, 15(2), 990. <https://doi.org/10.18549/PharmPract.2017.02.990>
- American Association of Colleges of Nursing. (n.d.). Academic nursing responds to the opioid epidemic. Retrieved August 20, 2019, from <https://www.aacnnursing.org/Policy-Advocacy/Opioids>
- American Cancer Society. (2016, September 27). Final CDC opioid prescribing guideline could have unintended consequences for cancer survivors living with chronic pain. Retrieved December 2, 2018, from American Cancer Society website: <https://www.fightcancer.org/releases/final-cdc-opioid-prescribing-guideline-could-have-unintended-consequences-cancer-survivors>
- American Medical Association. (n.d.). Support comprehensive treatment for pain and substance use disorders. Retrieved October 4, 2018, from End the Opioid Epidemic website: <https://www.end-opioid-epidemic.org/treatment/>
- American Nurses Association. (2018a). The ethical responsibility to manage pain and the suffering it causes. Retrieved from <https://www.nursingworld.org/~495e9b/globalassets/docs/ana/ethics/theethicalresponsibilitytomanagepainandthesufferingitcauses2018.pdf>

- American Nurses Association. (2018b). The opioid epidemic: The evolving role of nursing. Retrieved August 19, 2019, from https://www.ncsbn.org/2018_ANA_Opioid_Epidemic.pdf
- Baehren, D. F., Marco, C. A., Droz, D. E., Sinha, S., Callan, E. M., & Akpunonu, P. (2010). A statewide prescription monitoring program affects emergency department prescribing behaviors. *Annals of Emergency Medicine*, 56(1), 19-23.e3. <https://doi.org/10.1016/j.annemergmed.2009.12.011>
- Baker, D. W. (2017). The Joint Commission's pain standards: Origins and evolution. Retrieved September 23, 2017, from https://www.jointcommission.org/assets/1/6/Pain_Std_History_Web_Version_05122017.pdf
- Bao, Y., Pan, Y., Taylor, A., Radakrishnan, S., Luo, F., Pincus, H. A., & Schackman, B. R. (2016). Prescription drug monitoring programs are associated with sustained reductions in opioid prescribing by physicians. *Health Affairs*, 35(6), 1045–1051. <https://doi.org/10.1377/hlthaff.2015.1673>
- Barbera, L., Sutradhar, R., Chu, A., Seow, H., Earle, C. C., O'Brien, M. A., ... Howell, D. (2017). Has province-wide symptom screening changed opioid prescribing rates in older patients with cancer? *Journal of Oncology Practice*, 13(11), e927–e934. <https://doi.org/10.1200/JOP.2017.025494>
- Barbera, L., Sutradhar, R., Chu, A., Seow, H., Howell, D., Earle, C. C., ... DeAngelis, C. (2017). Opioid prescribing among cancer and non-cancer patients: Time trend analysis in the elderly using administrative data. *Journal of Pain and Symptom Management*, 54(4), 484-492.e1. <https://doi.org/10.1016/j.jpainsymman.2017.07.017>
- Barclay, J. S., Owens, J. E., & Blackhall, L. J. (2014). Screening for substance abuse risk in cancer patients using the Opioid Risk Tool and urine drug screen. *Supportive Care in Cancer*, 22(7), 1883–1888. <https://doi.org/10.1007/s00520-014-2167-6>
- Barnes, H., McDonald, J., Smallwood, N., & Manser, R. (2016). Opioids for treating breathlessness at the end of life. *Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD011008.pub2>
- Barnett, M. L., Olenski, A. R., & Jena, A. B. (2017). Opioid-prescribing patterns of emergency physicians and risk of long-term use. *New England Journal of Medicine*, 376(7), 663–673. <https://doi.org/10.1056/NEJMs1610524>

- Bartley, E. J., Boissoneault, J., Vargovich, A. M., Wandner, L. D., Hirsh, A. T., Lok, B. C., ... Robinson, M. E. (2015). The influence of health care professional characteristics on pain management decisions. *Pain Medicine*, 16(1), 99–111. <https://doi.org/10.1111/pme.12591>
- Bassah, N., Seymour, J., & Cox, K. (2014). A modified systematic review of research evidence about education for pre-registration nurses in palliative care. *BMC Palliative Care*, 13. <https://doi.org/10.1186/1472-684X-13-56>
- Bernhardt, M. B., Taylor, R. S., Hagan, J. L., Patel, N., Chumpitazi, C. E., Fox, K. A., & Glover, C. (2017). Evaluation of opioid prescribing after rescheduling of hydrocodone-containing products. *American Journal of Health-System Pharmacy*, 74(4), 2046–2053. <https://doi.org/10.2146/ajhp160548>
- Blinderman, C. D., & Billings, J. A. (2015). Comfort care for patients dying in the hospital. *New England Journal of Medicine*, 373(26), 2549–2561. <https://doi.org/10.1056/NEJMr1411746>
- Borgsteede, S. D., Deliens, L., Zuurmond, W. W. A., Schellevis, F. G., Willems, D. L., Van der Wal, G., & van Eijk, J. Th. M. (2009). Prescribing of pain medication in palliative care. A survey in general practice. *Pharmacoepidemiology and Drug Safety*, 18(1), 16–23. <https://doi.org/10.1002/pds.1678>
- Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global Qualitative Nursing Research*, 4, 233339361774228. <https://doi.org/10.1177/2333393617742282>
- Breuer, B., Cruciani, R., & Portenoy, R. K. (2010). Pain management by primary care physicians, pain physicians, chiropractors, and acupuncturists: A national survey. *Southern Medical Journal*, 103(8), 738–747. <https://doi.org/10.1097/SMJ.0b013e3181e74ede>
- Buchman, D. Z., Leece, P., & Orkin, A. (2017). The epidemic as stigma: The bioethics of opioids. *The Journal of Law, Medicine & Ethics*, 45(4), 607–620. <https://doi.org/10.1177/1073110517750600>
- Bulls, H. W., Hoogland, A. I., Craig, D., Paice, J., Chang, Y. D., Oberoi-Jassal, R., ... Jim, H. S. L. (2019). Cancer and opioids: Patient experiences with stigma (COPES)—a pilot study. *Journal of Pain and Symptom Management*, 57(4), 816–819. <https://doi.org/10.1016/j.jpainsymman.2019.01.013>
- Burgess, D. J., Dovidio, J., Phelan, S., & Van Ryn, M. (2011). The effect of medical authoritarianism on physicians' treatment decisions and attitudes regarding

- chronic pain. *Journal of Applied Social Psychology*, 41(6), 1399–1420.
<https://doi.org/10.1111/j.1559-1816.2011.00759.x>
- Burgess, D. J., Nelson, D. B., Gravely, A. A., Bair, M. J., Kerns, R. D., Higgins, D. M., ... Partin, M. R. (2014). Racial differences in prescription of opioid analgesics for chronic noncancer pain in a national sample of veterans. *The Journal of Pain: Official Journal of the American Pain Society*, 15(4), 447–455.
<https://doi.org/10.1016/j.jpain.2013.12.010>
- Burgess, D. J., Phelan, S., Workman, M., Hagel, E., Nelson, D. B., Fu, S. S., ... van Ryn, M. (2014). The effect of cognitive load and patient race on physicians' decisions to prescribe opioids for chronic low back pain: A randomized trial. *Pain Medicine (Malden, Mass.)*, 15(6), 965–974. <https://doi.org/10.1111/pme.12378>
- Cagle, J. G., Zimmerman, S., Cohen, L. W., Porter, L. S., Hanson, L. C., & Reed, D. (2015). EMPOWER: An intervention to address barriers to pain management in hospice. *Journal of Pain and Symptom Management*, 49(1), 1–12.
<https://doi.org/10.1016/j.jpainsymman.2014.05.007>
- Case, A., & Deaton, A. (2017). Mortality and morbidity in the 21st century. *Brookings Papers on Economic Activity*, 397.
- Caulkins, J. P., & Nicosia, N. (2010). What economics can contribute to the addiction sciences. *Addiction*, 105(7), 1156–1163. <https://doi.org/10.1111/j.1360-0443.2010.02915.x>
- Center for Drug Evaluation and Research. (2018). Postmarket drug safety information for patients and providers—Abuse-deterrent opioid analgesics. Retrieved March 29, 2019, from <https://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/ucm600788.htm>
- Centers for Disease Control and Prevention. (2017a). 10 leading causes of injury deaths by age group highlighting unintentional injury deaths, United States, 2017. Retrieved March 29, 2019, from https://www.cdc.gov/injury/images/lc-charts/leading_causes_of_death_by_age_group_unintentional_2017_1100w850h.jpg
- Centers for Disease Control and Prevention. (2017b). Drug overdose death data. Retrieved September 24, 2017, from <https://www.cdc.gov/drugoverdose/data/statedeaths.html>

- Centers for Disease Control and Prevention. (2017c). Guideline for prescribing opioids for chronic pain. Retrieved July 11, 2017, from <https://www.cdc.gov/drugoverdose/prescribing/guideline.html>
- Centers for Disease Control and Prevention. (2017d). Prescription opioid overdose data. Retrieved July 9, 2017, from <https://www.cdc.gov/drugoverdose/data/overdose.html>
- Centers for Disease Control and Prevention. (2017e). Prescription opioids. Retrieved September 23, 2017, from <https://www.cdc.gov/drugoverdose/opioids/prescribed.html>
- Chi, N. C., Demir, G., Pike, K. C., Washington, K., & Oliver, D. P. (2018). Pain management concerns from the hospice family caregivers' perspective. *American Journal of Hospice and Palliative Medicine*®, 35(4), 601–611. <https://doi.org/10.1177/1049909117729477>
- Childers, J. W., & Arnold, R. M. (2012). "I feel uncomfortable 'calling a patient out'": Educational needs of palliative medicine fellows in managing opioid misuse. *Journal of Pain and Symptom Management*, 43(2), 253–260. <https://doi.org/10.1016/j.jpainsymman.2011.03.009>
- Childers, J. W., King, L. A., & Arnold, R. M. (2015). Chronic pain and risk factors for opioid misuse in a palliative care clinic. *American Journal of Hospice and Palliative Medicine*®, 32(6), 654–659. <https://doi.org/10.1177/1049909114531445>
- Chiu, A. S., Jean, R. A., Hoag, J. R., Freedman-Weiss, M., Healy, J. M., & Pei, K. Y. (2018). Association of lowering default pill counts in electronic medical record systems with postoperative opioid prescribing. *JAMA Surgery*, 153(11), 1012–1019. <https://doi.org/10.1001/jamasurg.2018.2083>
- Click, I. A., Basden, J. A., Bohannon, J. M., Anderson, H., & Tudiver, F. (2018). Opioid prescribing in rural family practices: A qualitative study. *Substance Use & Misuse*, 53(4), 533–540. <https://doi.org/10.1080/10826084.2017.1342659>
- Courteau, C., Chaput, G., Musgrave, L., & Khadoury, A. (2018). Patients with advanced cancer: When, why, and how to refer to palliative care services. *Current Oncology*, 25(6), 403–408. <https://doi.org/10.3747/co.25.4453>
- Courtwright, D. T. (2009). *Dark paradise*. Cambridge, MA: Harvard University Press.

- Coyne, P., Mulvenon, C., & Paice, J. A. (2018). American Society for Pain Management Nursing and Hospice and Palliative Nurses Association position statement: Pain management at the end of life. *Pain Management Nursing*, 19(1), 3–7. <https://doi.org/10.1016/j.pmn.2017.10.019>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (Fifth edition). Los Angeles, CA: SAGE.
- Currie, J., & Schnell, M. (2018, August 20). A closer look at how the opioid epidemic affects employment. *Harvard Business Review*. Retrieved from <https://hbr.org/2018/08/a-closer-look-at-how-the-opioid-epidemic-affects-employment>
- Cushman, P. A., Liebschutz, J. M., Hodgkin, J. G., Shanahan, C. W., White, J. L., Hardesty, I., & Alford, D. P. (2017). What do providers want to know about opioid prescribing? A qualitative analysis of their questions. *Substance Abuse*, 38(2), 222–229. <https://doi.org/10.1080/08897077.2017.1296525>
- Darnall, B. D., Juurlink, D., Kerns, R. D., Mackey, S., Van Dorsten, B., Humphreys, K., ... Lovejoy, T. (2018). International stakeholder community of pain experts and leaders call for an urgent action on forced opioid tapering. *Pain Medicine*. <https://doi.org/10.1093/pm/pny228>
- Dasgupta, N., Creppage, K., Austin, A., Ringwalt, C., Sanford, C., & Proescholdbell, S. K. (2014). Observed transition from opioid analgesic deaths toward heroin. *Drug and Alcohol Dependence*, 145, 238–241. <https://doi.org/10.1016/j.drugalcdep.2014.10.005>
- Dickason, R. M., Chauhan, V., Mor, A., Ibler, E., Kuehnle, S., Mahoney, D., ... Dalawari, P. (2015). Racial differences in opiate administration for pain relief at an academic emergency department. *Western Journal of Emergency Medicine*, 16(3), 372–380. <https://doi.org/10.5811/westjem.2015.3.23893>
- Dillman, D. A., Smyth, J. D., & Christian, L. M. (2014). *Internet, phone, mail, and mixed-mode surveys: The tailored design method* (4th edition). Hoboken, NJ: Wiley.
- Dobscha, S. K., Corson, K., Flores, J. A., Tansill, E. C., & Gerrity, M. S. (2008). Veterans Affairs primary care clinicians' attitudes toward chronic pain and correlates of opioid prescribing rates. *Pain Medicine*, 9(5), 564–571. <https://doi.org/10.1111/j.1526-4637.2007.00330.x>

- Drug Policy Alliance. (n.d.). A brief history of the drug war. Retrieved March 29, 2019, from Drug Policy Alliance website: <http://www.drugpolicy.org/issues/brief-history-drug-war>
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- Epstein, E. G., & Hamric, A. B. (2009). Moral distress, moral residue, and the crescendo effect. *Journal of Clinical Ethics*, 20(4), 330–342.
- Erlingsson, C., & Brysiewicz, P. (2017). A hands-on guide to doing content analysis. *African Journal of Emergency Medicine*, 7(3), 93–99. <https://doi.org/10.1016/j.afjem.2017.08.001>
- Field, T. S., Cadoret, C. A., Brown, M. L., Ford, M., Greene, S. M., Hill, D., ... Zapka, J. M. (2002). Surveying physicians: Do components of the “Total Design Approach” to optimizing survey response rates apply to physicians? *Medical Care*, 40(7), 596–605.
- Finley, E. P., Garcia, A., Rosen, K., McGeary, D., Pugh, M. J., & Potter, J. S. (2017). Evaluating the impact of prescription drug monitoring program implementation: A scoping review. *BMC Health Services Research*, 17(1), 420. <https://doi.org/10.1186/s12913-017-2354-5>
- Fisch, M. J., Lee, J.-W., Weiss, M., Wagner, L. I., Chang, V. T., Cella, D., ... Cleeland, C. S. (2012). Prospective, observational study of pain and analgesic prescribing in medical oncology outpatients with breast, colorectal, lung, or prostate cancer. *Journal of Clinical Oncology*, 30(16), 1980–1988. <https://doi.org/10.1200/JCO.2011.39.2381>
- Fleming, M. L., Bapat, S. S., & Varisco, T. J. (2018). Using the theory of planned behavior to investigate community pharmacists’ beliefs regarding engaging patients about prescription drug misuse. *Research in Social and Administrative Pharmacy*. <https://doi.org/10.1016/j.sapharm.2018.10.027>
- Franklin, G. M., Fulton-Kehoe, D., Turner, J. A., Sullivan, M. D., & Wickizer, T. M. (2013). Changes in opioid prescribing for chronic Pain in Washington State. *The Journal of the American Board of Family Medicine*, 26(4), 394–400. <https://doi.org/10.3122/jabfm.2013.04.120274>
- Gabbard, J., Jordan, A., Mitchell, J., Corbett, M., White, P., & Childers, J. (2018). Dying on hospice in the midst of an opioid crisis: What should we do now? *American*

Journal of Hospice and Palliative Medicine, 104990911880666.
<https://doi.org/10.1177/1049909118806664>

- Gao, W., Gulliford, M., & Higginson, I. J. (2011). Prescription patterns of analgesics in the last 3 months of life: A retrospective analysis of 10202 lung cancer patients. *British Journal of Cancer*, 104(11), 1704–1710.
<https://doi.org/10.1038/bjc.2011.150>
- Gardiner, C., Gott, M., Ingleton, C., Hughes, P., Winslow, M., & Bennett, M. I. (2012). Attitudes of health care professionals to opioid prescribing in end-of-life care: A qualitative focus group study. *Journal of Pain and Symptom Management*, 44(2), 206–214. <https://doi.org/10.1016/j.jpainsymman.2011.09.008>
- Gomes, T., Juurlink, D., Yao, Z., Camacho, X., Paterson, J. M., Singh, S., ... Mamdani, M. (2014). Impact of legislation and a prescription monitoring program on the prevalence of potentially inappropriate prescriptions for monitored drugs in Ontario: A time series analysis. *CMAJ Open*, 2(4), E256–E261.
<https://doi.org/10.9778/cmajo.20140027>
- Gomes, T., Tadrous, M., Mamdani, M. M., Paterson, J. M., & Juurlink, D. N. (2018). The burden of opioid-related mortality in the United States. *JAMA Network Open*, 1(2), e180217–e180217. <https://doi.org/10.1001/jamanetworkopen.2018.0217>
- Haegerich, T. M., Paulozzi, L. J., Manns, B. J., & Jones, C. M. (2014). What we know, and don't know, about the impact of state policy and systems-level interventions on prescription drug overdose. *Drug and Alcohol Dependence*, 145, 34–47.
<https://doi.org/10.1016/j.drugalcdep.2014.10.001>
- Hahn, C. (2008). *Doing qualitative research using your computer: A practical guide*. Los Angeles, CA: SAGE.
- Haider, A., Zhukovsky, D. S., Meng, Y. C., Baidoo, J., Tanco, K. C., Stewart, H. A., ... Bruera, E. (2017). Opioid prescription trends among patients with cancer referred to outpatient palliative care over a 6-year period. *Journal of Oncology Practice*, 13(12), e972–e981. <https://doi.org/10.1200/JOP.2017.024901>
- Hanlon, J. T., Perera, S., Sevic, M. A., Rodriguez, K. L., & Jaffe, E. J. (2010). Pain and its treatment in older nursing home hospice/palliative care residents. *Journal of the American Medical Directors Association*, 11(8), 579–583.
<https://doi.org/10.1016/j.jamda.2009.11.014>
- Harle, C. A., Bauer, S. E., Hoang, H. Q., Cook, R. L., Hurley, R. W., & Fillingim, R. B. (2015). Decision support for chronic pain care: How do primary care physicians

- decide when to prescribe opioids? a qualitative study. *BMC Family Practice*, 16(1). <https://doi.org/10.1186/s12875-015-0264-3>
- Heneka, N., Shaw, T., Azzi, C., & Phillips, J. L. (2018). Clinicians' perceptions of medication errors with opioids in cancer and palliative care services: A priority setting report. *Supportive Care in Cancer*, 26(10), 3315–3318. <https://doi.org/10.1007/s00520-018-4231-0>
- Herr, K., Titler, M., Fine, P., Sanders, S., Cavanaugh, J., Swegle, J., ... Tang, X. (2010). Assessing and treating pain in hospices: Current state of evidence-based practices. *Journal of Pain and Symptom Management*, 39(5), 803–819. <https://doi.org/10.1016/j.jpainsymman.2009.09.025>
- Hooten, W. M., & Bruce, B. K. (2011). Beliefs and attitudes about prescribing opioids among healthcare providers seeking continuing medical education. *Journal of Opioid Management*, 7(6), 417–424.
- Howes, J. (2015). Nurses' perceptions of medication use at the end of life in an acute care setting. *Journal of Hospice & Palliative Nursing*, 17(6), 508. <https://doi.org/10.1097/NJH.0000000000000192>
- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. <https://doi.org/10.1177/1049732305276687>
- Hunnicutt, J. N., Tjia, J., & Lapane, K. L. (2017). Hospice use and pain management in elderly nursing home residents with cancer. *Journal of Pain and Symptom Management*, 53(3), 561–570. <https://doi.org/10.1016/j.jpainsymman.2016.10.369>
- Jamison, R. N., Sheehan, K. A., Scanlan, E., Matthews, M., & Ross, E. L. (2014). Beliefs and attitudes about opioid prescribing and chronic pain management: Survey of primary care providers. *Journal of Opioid Management*, 10(6), 375–382. <https://doi.org/10.5055/jom.2014.0234>
- Jonas, A. B., Young, A. M., Oser, C. B., Leukefeld, C. G., & Havens, J. R. (2012). OxyContin® as currency: OxyContin® use and increased social capital among rural Appalachian drug users. *Social Science & Medicine*, 74(10), 1602–1609. <https://doi.org/10.1016/j.socscimed.2011.12.053>
- Jones, G. H., Bruera, E., Abdi, S., & Kantarjian, H. M. (2018). The opioid epidemic in the United States: Overview, origins, and potential solutions. *Cancer*, 124(22), 4279–4286. <https://doi.org/10.1002/cncr.31713>

- Kennedy-Hendricks, A., Busch, S. H., McGinty, E. E., Bachhuber, M. A., Niederdeppe, J., Gollust, S. E., ... Barry, C. L. (2016). Primary care physicians' perspectives on the prescription opioid epidemic. *Drug and Alcohol Dependence, 165*, 61–70. <https://doi.org/10.1016/j.drugalcdep.2016.05.010>
- Kennedy-Hendricks, A., Richey, M., McGinty, E. E., Stuart, E. A., Barry, C. L., & Webster, D. W. (2016). Opioid overdose deaths and Florida's crackdown on pill mills. *American Journal of Public Health, 106*(2), 291–297.
- Keyes, K. M., Cerdá, M., Brady, J. E., Havens, J. R., & Galea, S. (2014). Understanding the rural–urban differences in nonmedical prescription opioid use and abuse in the United States. *American Journal of Public Health, 104*(2), e52–e59.
- Kim, H., Sefcik, J. S., & Bradway, C. (2017). Characteristics of qualitative descriptive studies: A systematic review. *Research in Nursing & Health, 40*(1), 23–42. <https://doi.org/10.1002/nur.21768>
- Kirou-Mauro, A. M., Hird, A., Wong, J., Sinclair, E., Barnes, E. A., Tsao, M., ... Chow, E. (2009). Has pain management in cancer patients with bone metastases improved? A seven-year review at an outpatient palliative radiotherapy clinic. *Journal of Pain and Symptom Management, 37*(1), 77–84. <https://doi.org/10.1016/j.jpainsymman.2007.12.014>
- Knight, K. R., Kushel, M., Chang, J. S., Zamora, K., Ceasar, R., Hurstak, E., & Miaskowski, C. (2017). Opioid pharmacovigilance: A clinical-social history of the changes in opioid prescribing for patients with co-occurring chronic non-cancer pain and substance use. *Social Science & Medicine, 186*, 87–95. <https://doi.org/10.1016/j.socscimed.2017.05.043>
- Kolodny, A., Courtwright, D. T., Hwang, C. S., Kreiner, P., Eadie, J. L., Clark, T. W., & Alexander, G. C. (2015). The prescription opioid and heroin crisis: A public health approach to an epidemic of addiction. *Annual Review of Public Health, 36*(1), 559–574. <https://doi.org/10.1146/annurev-publhealth-031914-122957>
- Kuehn, B. M. (2014). CDC: Major disparities in opioid prescribing among states: Some states crack down on excess prescribing. *Journal of the American Medical Association, 312*(7), 684–686. <https://doi.org/10.1001/jama.2014.9253>
- Kumar, K. H., & Elavarasi, P. (2016). Definition of pain and classification of pain disorders. *Journal of Advanced Clinical & Research Insights, 3*, 87–90. <https://doi.org/10.15713/ins.jcri.112>

- Kwon, J. H., Hui, D., Chisholm, G., Hong, W. T., Nguyen, L., & Bruera, E. (2013). Experience of barriers to pain management in patients receiving outpatient palliative care. *Journal of Palliative Medicine*, 16(8), 908–914. <https://doi.org/10.1089/jpm.2012.0610>
- Kwon, J. H., Oh, S. Y., Chisholm, G., Lee, J.-A., Lee, J. J., Park, K. W., ... Bruera, E. (2013). Predictors of high score patient-reported barriers to controlling cancer pain: A preliminary report. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, 21(4). <https://doi.org/10.1007/s00520-012-1646-x>
- Leung, P. T. M., Macdonald, E. M., Stanbrook, M. B., Dhalla, I. A., & Juurlink, D. N. (2017). A 1980 Letter on the risk of opioid addiction. *New England Journal of Medicine*, 376(22), 2194–2195. <https://doi.org/10.1056/NEJMc1700150>
- Levy, B., Paulozzi, L., Mack, K. A., & Jones, C. M. (2015). Trends in opioid analgesic-prescribing rates by specialty, U.S., 2007–2012. *American Journal of Preventive Medicine*, 49(3), 409–413. <https://doi.org/10.1016/j.amepre.2015.02.020>
- Lofwall, M. R., Moody, D. E., Fang, W. B., Nuzzo, P. A., & Walsh, S. L. (2012). Pharmacokinetics of intranasal crushed OxyContin and intravenous oxycodone in nondependent prescription opioid abusers. *Journal of Clinical Pharmacology*, 52(4), 600–606. <https://doi.org/10.1177/0091270011401620>
- Lorenz, K. A., Lynn, J., Dy, S. M., Shugarman, L. R., Wilkinson, A., Mularski, R. A., ... Shekelle, P. G. (2008). Evidence for improving palliative care at the end of life: A systematic review. *Annals of Internal Medicine*, 148(2), 147. <https://doi.org/10.7326/0003-4819-148-2-200801150-00010>
- Losby, J. L., Hyatt, J. D., Kanter, M. H., Baldwin, G., & Matsuoka, D. (2017). Safer and more appropriate opioid prescribing: A large healthcare system's comprehensive approach. *Journal of Evaluation in Clinical Practice*, 23(6), 1173–1179. <https://doi.org/10.1111/jep.12756>
- Lum, P. J., Little, S., Botsko, M., Hersh, D., Thawley, R. E., Egan, J. E., ... Fiellin, D. A. (2011). Opioid-prescribing practices and provider confidence recognizing opioid analgesic abuse in HIV primary care settings. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 56, S91–S97. <https://doi.org/10.1097/QAI.0b013e31820a9a82>
- Macerollo, A. A., Mack, D. O., Oza, R., Bennett, I. M., & Wallace, L. S. (2014). Academic family medicine physicians' confidence and comfort with opioid

- analgesic prescribing for patients with chronic nonmalignant pain. *Journal of Opioid Management*, 10(4), 255–261. <https://doi.org/10.5055/jom.2014.0213>
- Madras, B. K. (2017). The surge of opioid use, addiction, and overdoses: Responsibility and response of the US health care system. *JAMA Psychiatry*, 74(5), 441–442. <https://doi.org/10.1001/jamapsychiatry.2017.0163>
- Manchikanti, L., Helm, S., Fellows, B., Janata, J., Pampati, V., Grider, J., & Boswell, M. (2012). Opioid epidemic in the United States. *Pain Physician*, 15(1), 2150–1149.
- Manjiani, D., Paul, D. B., Kunnumpurath, S., Kaye, A. D., & Vadivelu, N. (2014). Availability and utilization of opioids for pain management. *Global issues*, 14(2), 8.
- Matto, H. C., & Cleaveland, C. L. (2016). A social-spatial lens to examine poverty, violence, and addiction. *Journal of Social Work Practice in the Addictions*, 16(1–2), 7–23. <https://doi.org/10.1080/1533256x.2016.1165113>
- Maxwell, J. C. (2011). The prescription drug epidemic in the United States: A perfect storm: The prescription drug epidemic in the USA. *Drug and Alcohol Review*, 30(3), 264–270. <https://doi.org/10.1111/j.1465-3362.2011.00291.x>
- McHugh, R. K., Nielsen, S., & Weiss, R. D. (2015). Prescription drug abuse: From epidemiology to public policy. *Journal of Substance Abuse Treatment*, 48(1), 1–7. <https://doi.org/10.1016/j.jsat.2014.08.004>
- McKinlay, J. B., Trachtenberg, F., Marceau, L. D., Katz, J. N., & Fischer, M. A. (2014). Effects of patient medication requests on physician prescribing behavior: Results of a factorial experiment. *Medical Care*, 52(4), 294–299. <https://doi.org/10.1097/MLR.0000000000000096>
- Meier, E. A., Gallegos, J. V., Thomas, L. P. M., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): Literature review and a call for research and public dialogue. *The American Journal of Geriatric Psychiatry*, 24(4), 261–271. <https://doi.org/10.1016/j.jagp.2016.01.135>
- Meit, M., Heffernan, M., & Tanenbaum, E. (2017). Appalachian diseases of despair. Retrieved September 20, 2017, from https://www.arc.gov/assets/research_reports/AppalachianDiseasesofDespairAugust2017.pdf
- Merlin, J. S., Patel, K., Thompson, N., Kapo, J., Keefe, F., Liebschutz, J., ... Ritchie, C. S. (2018). Managing chronic pain in cancer survivors prescribed long-term opioid therapy: A national survey of ambulatory palliative care providers. *Journal of*

Pain and Symptom Management.

<https://doi.org/10.1016/j.jpainsymman.2018.10.493>

- Michael, S. S., Babu, K. M., Androski, C., & Reznick, M. A. (2018). Effect of a data-driven intervention on opioid prescribing intensity among emergency department providers: A randomized controlled trial. *Academic Emergency Medicine*, 25(5), 482–493. <https://doi.org/10.1111/acem.13400>
- Michna, E., Kirson, N. Y., Shei, A., Birnbaum, H. G., & Ben-Joseph, R. (2014). Use of prescription opioids with abuse-deterrent technology to address opioid abuse. *Current Medical Research and Opinion*, 30(8), 1589–1598. <https://doi.org/10.1185/03007995.2014.915803>
- Montano, D. E., & Kasprzyk, D. (2015). Theory of Reasoned Action, Theory of Planned Behavior, and the Integrated Behavioral Model. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior: Theory, research, and practice* (Fifth edition). San Francisco, CA: Jossey-Bass.
- Muir, J. C., Scheffey, C., Young, H. M., Vilches, A. O., Davis, M. S., & Connor, S. R. (2013). Opioid prescribing practices before and after initiation of palliative care in outpatients. *Journal of Pain and Symptom Management*, 45(6), 1107–1111. <https://doi.org/10.1016/j.jpainsymman.2012.06.006>
- Müller-Busch, H. C., Lindena, G., Tietze, K., & Woskanjan, S. (2005). Opioid switch in palliative care, opioid choice by clinical need and opioid availability. *European Journal of Pain*, 9(5), 571–571. <https://doi.org/10.1016/j.ejpain.2004.12.003>
- National Academy of Medicine. (n.d.). Opioid collaborative network organizations. Retrieved August 20, 2019, from National Academy of Medicine website: <https://nam.edu/programs/action-collaborative-on-counteracting-the-u-s-opioid-epidemic/network-organizations/>
- National Institute on Aging. (2017). What are palliative care and hospice care? Retrieved from <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care>
- Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description – the poor cousin of health research? *BMC Medical Research Methodology*, 9(1). <https://doi.org/10.1186/1471-2288-9-52>
- Netherland, J., & Hansen, H. (2017). White opioids: Pharmaceutical race and the war on drugs that wasn't. *BioSocieties*, 12(2), 217–238. <https://doi.org/10.1057/biosoc.2015.46>

- North Carolina General Assembly. (n.d.). STOP Act overview. Retrieved December 2, 2018, from <https://www.ncleg.net/DocumentSites/Committees/NCCFTF/Presentations/2017-2018/STOP%20Act%20Overview%20CFTF%209-26-2017.pdf>
- North Carolina Medical Board. (2017). The STOP Act summary. Retrieved October 11, 2017, from https://www.ncmedboard.org/images/uploads/article_images/The_STOP_Act_summary-OnLetterhead.pdf
- Nwokeji, E. D., Rascati, K. L., Brown, C. M., & Eisenberg, A. (2007). Influences of attitudes on family physicians' willingness to prescribe long-acting opioid analgesics for patients with chronic nonmalignant pain. *Clinical Therapeutics*, 29(11), 2589–2602. <https://doi.org/10.1016/j.clinthera.2007.12.007>
- Olmstead, T. A., Alessi, S. M., Kline, B., Pacula, R. L., & Petry, N. M. (2015). The price elasticity of demand for heroin: Matched longitudinal and experimental evidence. *Journal of Health Economics*, 41, 59–71. <https://doi.org/10.1016/j.jhealeco.2015.01.008>
- Organization for Economic Cooperation and Development. (2018). OECD economic surveys: United States. Retrieved from <http://www.oecd.org/eco/surveys/Overview-United-States-2018-OECD.pdf>
- Oyler, D. R., Deep, K. S., & Chang, P. K. (2018). Opioid use in the acute setting: A survey of providers at an academic medical center. *Journal of Opioid Management*, 14(3), 203–210. <https://doi.org/10.5055/jom.2018.0450>
- Pearson, A. C., Moman, R. N., Moeschler, S. M., Eldrige, J. S., & Hooten, W. M. (2017). Provider confidence in opioid prescribing and chronic pain management: Results of the Opioid Therapy Provider Survey. *Journal of Pain Research*, 10, 1395–1400. <https://doi.org/10.2147/JPR.S136478>
- Perry, S., & Heidrich, G. (1982). Management of pain during debridement: A survey of U.S. burn units. *Pain*, 13(3), 267–280.
- Pinkerton, R., & Hardy, J. R. (2017). Opioid addiction and misuse in adult and adolescent patients with cancer. *Internal Medicine Journal*, 47(6), 632–636. <https://doi.org/10.1111/imj.13449>
- Pomerleau, A. C., Schrager, J. D., & Morgan, B. W. (2016). Pilot study of the importance of factors affecting emergency department opioid analgesic prescribing decisions.

Journal of Medical Toxicology, 12(3), 282–288. <https://doi.org/10.1007/s13181-016-0553-9>

Portenoy, R. K., Sibirceva, U., Smout, R., Horn, S., Connor, S., Blum, R. H., ... Fine, P. G. (2006). Opioid use and survival at the end of life: A survey of a hospice population. *Journal of Pain and Symptom Management*, 32(6), 532–540. <https://doi.org/10.1016/j.jpainsymman.2006.08.003>

Porter, J., & Jick, H. (1980). Addiction rare in patients treated with narcotics. *The New England Journal of Medicine*, 302(2), 123.

Quinn, T. M., & McLaughlin, G. T. (1973). The evolution of federal drug control legislation. *Catholic University Law Review*, 22(3), 43.

Quinones, S. (2016). *Dreamland: The true tale of America's opiate epidemic*. New York, NY: Bloomsbury Press.

Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology*, 11(1), 25–41. <https://doi.org/10.1080/14780887.2013.801543>

Rose, C. (2017). The war on drugs: An analysis of the effects of supply disruption on prices and purity. Retrieved from <https://core.ac.uk/download/pdf/47163058.pdf>

Rudd, R. A. (2016). Increases in drug and opioid-involved overdose deaths—United States, 2010–2015. *MMWR. Morbidity and Mortality Weekly Report*, 65. Retrieved from <https://www.cdc.gov/mmwr/volumes/65/wr/mm655051e1.htm>

Ruhm, C. J. (2017). Geographic variation in opioid and heroin involved drug poisoning mortality rates. *American Journal of Preventive Medicine*, 53(6), 745–753. <https://doi.org/10.1016/j.amepre.2017.06.009>

Rummans, T. A., Burton, M. C., & Dawson, N. L. (2018). How good intentions contributed to bad outcomes: The opioid crisis. *Mayo Clinic Proceedings*, 93(3), 344–350. <https://doi.org/10.1016/j.mayocp.2017.12.020>

Russell, B. J., Rowett, D., & Currow, D. C. (2014). Pro re nata prescribing in a population receiving palliative care: A prospective consecutive case note review. *Journal of the American Geriatrics Society*, 62(9), 1736–1740. <https://doi.org/10.1111/jgs.12981>

Sacco, P., Cagle, J. G., Moreland, M. L., & Camlin, E. A. S. (2017). Screening and assessment of substance use in hospice care: Examining content from a national

- sample of psychosocial assessments. *Journal of Palliative Medicine*, 20(8), 850–856. <https://doi.org/10.1089/jpm.2016.0538>
- Saldaña, J. (2016). *The coding manual for qualitative researchers* (Third edition). Los Angeles, CA: SAGE.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health*, 18(2), 179–183. <https://doi.org/10.1002/nur.4770180211>
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334–340. [https://doi.org/10.1002/1098-240X\(200008\)23:4<334::AID-NUR9>3.0.CO;2-G](https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G)
- Schenker, Y., Merlin, J. S., & Quill, T. E. (2018). Use of palliative care earlier in the disease course in the context of the opioid epidemic: Educational, research, and policy issues. *Journal of the American Medical Association*, 320(9), 871–872. <https://doi.org/10.1001/jama.2018.9739>
- Shaheen, P. E., LeGrand, S. B., Walsh, D., Estfan, B., Davis, M. P., Lagman, R. L., ... Cheema, B. (2010). Errors in opioid prescribing: A prospective survey in cancer pain. *Journal of Pain and Symptom Management*, 39(4), 702–711. <https://doi.org/10.1016/j.jpainsymman.2009.09.009>
- Signorelli, C., Wakefield, C. E., Fardell, J. E., Thornton-Benko, E., Emery, J., McLoone, J. K., ... ANZCHOG Survivorship Study Group. (2018). Recruiting primary care physicians to qualitative research: Experiences and recommendations from a childhood cancer survivorship study. *Pediatric Blood & Cancer*, 65(1). <https://doi.org/10.1002/pbc.26762>
- Sinnenberg, L. E., Wanner, K. J., Perrone, J., Barg, F. K., Rhodes, K. V., & Meisel, Z. F. (2017). What factors affect physicians' decisions to prescribe opioids in emergency departments? *MDM Policy & Practice*, 2(1), 238146831668100. <https://doi.org/10.1177/2381468316681006>
- Smith, R. J., Rhodes, K., Paciotti, B., Kelly, S., Perrone, J., & Meisel, Z. F. (2015). Patient perspectives of acute pain management in the era of the opioid epidemic. *Annals of Emergency Medicine*, 66(3), 246-252.e1. <https://doi.org/10.1016/j.annemergmed.2015.03.025>
- Spitz, A., Moore, A. A., Papaleontiou, M., Granieri, E., Turner, B. J., & Reid, M. C. (2011). Primary care providers' perspective on prescribing opioids to older adults with chronic non-cancer pain: A qualitative study. *BMC Geriatrics*, 11(1). <https://doi.org/10.1186/1471-2318-11-35>

- Substance Abuse and Mental Health Services Administration. (2017a). Kentucky meets the gold standard for prescription drug monitoring programs. Retrieved November 12, 2017, from <https://www.samhsa.gov/capt/tools-learning-resources/kentucky-meets-gold-standard-prescription-drug-monitoring-programs>
- Substance Abuse and Mental Health Services Administration. (2017b). Key substance use and mental health indicators in the United States: Results from the 2017 National Survey on Drug Use and Health. Retrieved October 7, 2018, from <https://www.samhsa.gov/data/report/2017-nsduh-annual-national-report>
- Tan, P. D., Barclay, J. S., & Blackhall, L. J. (2015). Do palliative care clinics screen for substance abuse and diversion? *Results of a national survey. Journal of Palliative Medicine, 18*(9), 752–757. <https://doi.org/10.1089/jpm.2015.0098>
- The Henry J. Kaiser Family Foundation. (2017). Opioid overdose deaths. Retrieved September 24, 2017, from <http://www.kff.org/state-category/health-status/opioids/>
- The National Alliance of Advocates for Buprenorphine Treatment. (2016). A history of opiate opioid laws in the United States. Retrieved October 10, 2018, from <https://www.naabt.org/laws.cfm>
- U.S. Department of Health and Human Services. (2018). Facing addiction in America: The Surgeon General's spotlight on opioids. Retrieved from Facing addiction in America: The Surgeon General's spotlight on opioids website: https://addiction.surgeongeneral.gov/sites/default/files/Spotlight-on-Opioids_09192018.pdf
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences, 15*(3), 398–405. <https://doi.org/10.1111/nhs.12048>
- van den Beuken-van Everdingen, M. H. J., de Rijke, J. M., Kessels, A. G., Schouten, H. C., van Kleef, M., & Patijn, J. (2007). High prevalence of pain in patients with cancer in a large population-based study in the Netherlands. *PAIN, 132*(3), 312–320. <https://doi.org/10.1016/j.pain.2007.08.022>
- Van Zee, A. (2009). The promotion and marketing of OxyContin: Commercial triumph, public health tragedy. *American Journal of Public Health, 99*(2), 221–227. <https://doi.org/10.2105/AJPH.2007.131714>
- Varilla, V., Schneiderman, H., & Keefe, S. (2015). No ceiling dose: Effective pain control with extraordinary opiate dosing in cancer. *Connecticut Medicine, 79*(9), 521–524.

- Verberkt, C. A., van den Beuken-van Everdingen, M. H. J., Schols, J. M. G. A., Datla, S., Dirksen, C. D., Johnson, M. J., ... Janssen, D. J. A. (2017). Respiratory adverse effects of opioids for breathlessness: A systematic review and meta-analysis. *The European Respiratory Journal*, 50(5). <https://doi.org/10.1183/13993003.01153-2017>
- Walden, G. (2018, October 24). H.R.6—115th Congress (2017-2018): SUPPORT for Patients and Communities Act. Retrieved December 2, 2018, from <https://www.congress.gov/bill/115th-congress/house-bill/6/text>
- Wee, B., & Hughes, N. (2007). Education in palliative care: Building a culture of learning. Retrieved from <http://www.oxfordscholarship.com/view/10.1093/acprof:oso/9780198569855.001.0001/acprof-9780198569855>
- Whitehouse, S. (2016, July 22). S.524 - 114th Congress (2015-2016): Comprehensive Addiction and Recovery Act of 2016. Retrieved December 2, 2018, from <https://www.congress.gov/bill/114th-congress/senate-bill/524>
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, 52(5), 546–553. <https://doi.org/10.1111/j.1365-2648.2005.03621.x>
- Wiffen, P., Derry, S., & Moore, R. (2014). Impact of morphine, fentanyl, oxycodone or codeine on patient consciousness, appetite and thirst when used to treat cancer pain. *Cochrane Database of Systematic Reviews*, (5). <https://doi.org/10.1002/14651858.CD011056.pub2>
- Wiffen, P. J., Wee, B., Derry, S., Bell, R. F., & Moore, R. A. (2017). Opioids for cancer pain - an overview of Cochrane reviews. *The Cochrane Database of Systematic Reviews*, 2017(7). <https://doi.org/10.1002/14651858.CD012592.pub2>
- Willis, D. G., Sullivan-Bolyai, S., Knafl, K., & Cohen, M. Z. (2016). Distinguishing features and similarities between descriptive phenomenological and qualitative description research. *Western Journal of Nursing Research*, 38(9), 1185–1204. <https://doi.org/10.1177/0193945916645499>
- Wilsey, B. L., Fishman, S. M., Ogden, C., Tsodikov, A., & Bertakis, K. D. (2008). Chronic pain management in the emergency department: A survey of attitudes and beliefs. *Pain Medicine*, 9(8), 1073–1080. <https://doi.org/10.1111/j.1526-4637.2007.00400.x>

- Wilson, C. M. (2017). Opioid campaigns' impact on advanced cancer and hospice and palliative care: An invited commentary. *Rehabilitation Oncology*, 35(2), 94–98.
- Wolfert, M. Z., Gilson, A. M., Dahl, J. L., & Cleary, J. F. (2010). Opioid analgesics for pain control: Wisconsin physicians' knowledge, beliefs, attitudes, and prescribing practices. *Pain Medicine*, 11(3), 425–434. <https://doi.org/10.1111/j.1526-4637.2009.00761.x>
- World Health Organization. (n.d.a). Definition of palliative care. Retrieved from <https://www.who.int/cancer/palliative/definition/en/>
- World Health Organization. (n.d.b). WHO's cancer pain ladder for adults. Retrieved August 16, 2019, from WHO website: <https://www.who.int/cancer/palliative/painladder/en/>
- Wright, E. R., Kooreman, H. E., Greene, M. S., Chambers, R. A., Banerjee, A., & Wilson, J. (2014). The iatrogenic epidemic of prescription drug abuse: County-level determinants of opioid availability and abuse. *Drug and Alcohol Dependence*, 138, 209–215. <https://doi.org/10.1016/j.drugalcdep.2014.03.002>
- Xierali, I. M., Hsiao, C.-J., Puffer, J. C., Green, L. A., Rinaldo, J. C. B., Bazemore, A. W., ... Phillips, R. L. (2013). The rise of electronic health record adoption among family physicians. *Annals of Family Medicine*, 11(1), 14–19. <https://doi.org/10.1370/afm.1461>
- Youngcharoen, P., Vincent, C., & Park, C. G. (2017). Theory of planned behavior constructs associated with nurses' pain assessment and pro re nata (PRN) opioid analgesic administration: A cross-sectional study. *Pain Management Nursing*, 18(3), 153–169. <https://doi.org/10.1016/j.pmn.2017.03.001>
- Ziegler, L., Mulvey, M., Blenkinsopp, A., Petty, D., & Bennett, M. I. (2016). Opioid prescribing for patients with cancer in the last year of life: A longitudinal population cohort study. *Pain*, 157(11), 2445–2451. <https://doi.org/10.1097/j.pain.0000000000000656>
- Zolot, J. (2016). The AACN recommends increased palliative care training in undergraduate nursing education. *AJN The American Journal of Nursing*, 116(5), 16. <https://doi.org/10.1097/01.NAJ.0000482949.65737.ae>

APPENDIX A

INTERVIEW GUIDE

Questions asked of all participants:

1. In your opinion, how has the opioid epidemic and related policies affected opioid prescribing in the specialty of hospice and palliative care? **(TPB Concept – Attitude)**
2. What factors are barriers or facilitators to you prescribing opioids in hospice and palliative care? **(TPB Concept - Perceived Behavioral Control)**
3. How would you describe the culture of opioid prescribing within your workplace? What about hospice/palliative care in general? **(TPB Concept – Subjective Norm)**
4. Do you intend to change your opioid prescribing practices as a result of the opioid epidemic and/or related policies? **(TPB Concept – Behavioral Intention)**

Follow up questions:

1. Describe a situation in which you have cared for a hospice or palliative care patient that has uncontrolled pain and limited access to opioids. Was this situation affected by either the opioid epidemic or related policies?
2. Are you familiar with the North Carolina STOP Act and the CDC guidelines related to opioid prescribing? How might these guidelines impact opioid prescribing in hospice and palliative care?
3. Do you have any advice to other hospice and palliative care clinicians prescribing in the era of the opioid epidemic?

APPENDIX B

DEMOGRAPHIC FORM

1. What is your gender? (Please circle the best option)
 - Male
 - Female
2. What is your age? (Please select the appropriate answer)
 - 20-30
 - 31-40
 - 41-50
 - 51-60
 - 61-70
 - >70
3. What type of medical/nursing license do you have? (Please circle the best option)
 - Physician
 - Nurse Practitioner
 - Physician Assistant
4. What is the primary location of your practice? (Select all that apply)
 - Hospital
 - Outpatient Hospice
 - Inpatient Hospice
 - Inpatient Palliative Care
 - Outpatient/Community Palliative Care
 - Clinic
 - Nursing or Assisted Living Facility
 - Other (Please Explain)
5. How many total years have you been in practice as a physician/nurse practitioner/physician assistant? (Please write the appropriate answer using numerical value)
6. How many total years have you been in practice in the setting of hospice/palliative care? (Please write the appropriate answer using numerical value)

APPENDIX C
INFORMATION SHEET

Research Study: The Opioid Epidemic and the Impact on Opioid Prescribing in Hospice and Palliative Care: A Qualitative Description

Investigator: Joshua Borders, DNP, NP-C, ACHPN, PhD Candidate

Faculty Advisor: Dr. Susan Letvak

Purpose of the Research Study: This study aims to describe the perceptions among hospice and palliative care clinicians of opioid prescribing associated with the opioid epidemic and related policies.

Risks: It is possible that the interview could prompt an emotional distress (rare, less than 1%) related to opioid prescribing, policies, or patient care. If you experience emotional distress, you should take a short break, talk with the investigator, or withdrawal from this study. If you continue to have emotional distress, you should seek professional help from your primary care provider or the local Crisis hotline (1-877-626-1772). Confidentiality breach is the second risk (rare <1%). To minimize risk the researcher will not collect any identifiable information. Data will be aggregated to protect your confidentiality. Pseudonyms will be used to analyze data and in publication. The investigator will only share non identified responses with the Faculty Advisor, unless required by law. The investigator will keep interview transcripts and field notes in a secured digital file. Demographic data will be destroyed once the investigator and the advisor have reviewed, summarized, and checked for accuracy. Only the summary information will be retained on a password protected and firewalled personal computer, with a backup on the UNCG server space for faculty advisor review and validation.

Benefits: Research will help fill the current knowledge gap of opioid prescribing related to the opioid epidemic in hospice and palliative care.

Time Required: It is estimated that this interview will take less than 60 minutes. You may be contacted in the future to participate in a second interview or to clarify responses from the first interview. You may opt not to be contacted for future participation.

Confidentiality: The information that you provide in this study will be handled confidentially. No private or identifiable information will be collected. Strategies to avoid this risk are noted above under RISKS.

Voluntary Participation: Your participation is completely voluntary.

Right to Withdraw: You have the right to withdraw from the study at any time. You may do this by informing the principal investigator.

Future Contact: You have the right to opt out of any future contact from this researcher.

Payment: You will receive a \$20 Amazon gift card for participation in this study.

If you have questions about the study, please contact: Joshua Borders, DNP, NP-C, ACHPN, PhD Candidate, University of North Carolina at Greensboro, [REDACTED], or Dr. Susan Letvak, [REDACTED]

If you have any concerns about your rights, how you are being treated, or if you have questions, want more information or have suggestions, please contact: Office of Research Integrity at UNCG at (855) 251-2351.

APPENDIX D

SAMPLE CODE BOOK

Categories	Subcategories	Code Descriptions and Data Sample	Examples of In Vivo Codes
Impact on the Patient	Undertreatment: Poor pain control/Limited access to opioids	<p>Codes refer to the perception of the clinician that patients have improperly controlled pain or limited access to opioids</p> <p>“So, patients who are nearing end of life, who may also have very heavy chronic disease burdens, they have to fight to get pain control. We see it time and time again.”</p> <p>“first seen by me for Palliative care and, uh, was under inadequate pain management for his metastatic to bone pain.”</p>	<p>not controlling their pain withdrawal symptoms they can't be honest fight to get pain control sub optimal regimens people are suffering legitimate pain Inadequate pain management we can't get rid of their pain totally in pretty serious pain their pain is under treated the pain was incapacitating.</p>
	Stigma/Victimization	<p>Codes refer to the identification of labels assigned to the patient by the healthcare team, implicit bias, stigma, or victimization of the patient due to the opioid epidemic.</p>	<p>pseudo addiction stereotypes of opioid addiction the drug seeker is inherently a bad patient have a label anywhere on their chart, it's over addiction or substance abuse</p>

		<p>“It’s stigma is what it is. The drug seeker is inherently a bad patient...it's not a medical term and we should stop using it.”</p> <p>“they were looking at him as someone who was potentially there to divert medications, to use some for ulterior gain, uh, that he had to sit in to room with, uh, two with, uh, interrogators.</p>	<p>drug seeker Major stigma have addictive personalities Potential for abuse drug addict divert medications, to use some for ulterior gain disturbance in their lives victims</p>
	Illicit use	<p>Codes refer to the illicit use of opioids by patients to achieve pain relief or the processes of addiction characterized by the clinician</p> <p>“We also have people who are using illicit drugs to control their pain because they can't get, uh, drugs in legal ways. They're taking it out of their relative's closet or they're having unusual urine drug screens because they're so desperate for this relief.”</p> <p>“People will become drug addicts. People</p>	<p>using illicit drugs addiction or substance abuse drug addicts suicide heroin diverters substance abuse and chronic pain chewing up their fentanyl they're getting it on the streets get a product off the street</p>

		will shoot themselves. I mean, you know, if you've got incredible pain, you're gonna find a way to get out of pain and it's gonna be, you know, heroin or suicide or something. And to me, that's not justifiable.”	
	Fear	<p>The codes refer to fear or concerns that patients or families have related to opioid prescribing</p> <p>“So, it's been this flip culture too, unexpected, unintended consequences where patients are saying, I don't want to be addicted. That's a hard one. Or family say don't give them that, you know, because they've heard, you know, how horrible Oxycontin is on TV.”</p> <p>“they also have their ears have heard about the opioid crisis and how it truly has ruined lives and they understand that.”</p>	<p>I don't want to be addicted. ruined lives I don't want to get addicted fears of addiction, fears of uh, hastening death</p>

Impact on the Clinician	Limited Changes Made to Individual Prescribing	<p>Codes refer to the perception of the clinician that their individual prescribing patterns have not been significantly impacted or changed due to the opioid epidemic or related policies.</p> <p>“I have zero fear from the STOP Act. It does not impact my practice. Zero. Um, I don't think about it. I don't consider it. I know it exists and I know what it says, but I also at the end of the day, feel pretty secure in how I prescribe opioids and under the circumstances that I prescribed them”</p> <p>“I mean I think as far as prescribing what I would prescribe, it hadn't changed that, I mean starting people on opioids, I can only speak to what I would've done. And I think I would, it hasn't really changed”</p>	<p>I have very few barriers zero fear from the STOP Act it hasn't really changed I didn't personally feel like I was contributing I wrote prescriptions all the time I did it anyway I do what I feel like I need to do I prioritize symptom management.</p>
	Careful prescribing/Use of prescribing protocols	Codes refer to identification of practices or policies	prescription drug monitoring program.

		<p>that relate to safe opioid prescribing</p> <p>“you need certain things in place to make sure that safe. So you need some type of prescription drug monitoring program.”</p> <p>“looking at dosages and for whatever reason like pill counts have become a much more important qualifier in the minds of some physicians whenever they're writing.”</p>	<p>opioid risk screening tool</p> <p>things in place to make sure that safe an exit strategy physicians have contributed to the problem</p> <p>thoughtful about how we prescribed assessment of risk</p> <p>I'm going to prescribe opioids.</p>
Impact on Nursing	Inappropriate Nursing Practices	<p>Codes refer to the perception of the clinician that nursing practices related to opioid administration are inappropriate.</p> <p>“So therefore patients, I think, who, um, maybe cognitively or are verbally unable to ask for PRN, like as needed medications don't get it. That's upsetting.”</p> <p>“I think that part of the, the cultural shift is coming particularly with newer nurses, is like</p>	<p>PRN...medications don't get it.</p> <p>pill counts</p> <p>phobia of giving as needed medications, not getting them</p> <p>they do give a lot of pushback</p> <p>don't even get a PRN medications</p> <p>I'm not getting any PRNs given</p>

		a phobia of giving people even appropriate doses of pain medications, um, because of their perceived, you know, possible bad side effects of it.”	
	Nurses as patient advocates	<p>Codes refer to the perception of the clinician that nurses are advocates for appropriate pain management</p> <p>“Um, introducing some long acting pain medication, uh, not a bad thing. Um, so I'm seeing more and more, uh, nurses being empowered, ask for that kind of thing and to hold the orders accountable for what's happening with the patient. So that is a good thing that's come out of it.”</p> <p>“it's very distressing for the nurses when people can't get medicine that they think that they should get. Um, and you know, and I think that they're willing to try alternatives and do whatever. But I do think, um, they feel,</p>	<p>nurses being empowered advocates</p> <p>They look at someone and say, this person's in pain leading kind of questions</p> <p>I would color it cherry picking the answer</p> <p>hard stop from the physicians</p> <p>play them off each other a little bit</p> <p>advocate for their person</p> <p>a hard stop</p> <p>validate the use of that drug</p> <p>biggest advocates</p> <p>anticipate needs and advocate for their patients.</p> <p>nurses call and beg nursing care when it comes to treatment</p>

		they feel that they're the patient advocates.”	
Impact on the Specialty	Limited Impact Within Hospice	<p>Codes refer to the perception that the specialty of hospice has had limited impact due to the opioid epidemic</p> <p>“The hospice industry as a whole is really stepping up to say we're going to provide comfort, dignity, the end of, at the end of life, no matter what that takes.”</p> <p>“I don't feel...that the majority of people who are being victims of the opioid crisis are hospice patients”</p>	<p>hospice world... the safest environment</p> <p>where do you kind of draw the line</p> <p>the definition of Palliative Care, look, it leaves it open.</p> <p>guidelines specifically exclude palliative care ability to follow up on people picking them up sooner.</p> <p>Victims not hospice patients</p>
	Organizational Problems: Leadership, Resources, Other Specialties	<p>These codes refer to the identification by the clinician of an organizational or system problem leading to a change in opioid prescribing. The most common factors identified are leadership issues, lack of resources, and problems with other specialties.</p> <p>“a lot of these things are in that kind of</p>	<p>lost to followup what's gonna happen when they leave here continue that whenever they leave here the way this practice is set up my boss I'm a consultant where are they going to go portrayals of risk so much fear like somebody is watching them</p>

		<p>lost to followup category where I just don't know what happens when they leave here.”</p> <p>“Can I find an oncologist, primary care physician, pain management specialist, somebody who feels comfortable enough or understands enough what my intent was to continue that whenever they leave here. Um, I think there are still big gaps across the country, but in particular I see it here where even with outpatient providers there, there's just a lack of, I guess follow up with agreeability to pick up that kind of responsibility for continuing prescribing.”</p>	<p>the DEA's going to come after them</p> <p>difficulty getting providers in the community to even prescribe</p> <p>it's hard to be the enforcer of regulation and policy</p> <p>they feel like they're overmedicating get somebody else to do it.</p> <p>you're going to be in the bullseye if you write opioids could hasten his demise</p> <p>Facilitating the death of the patient</p>
	Determination of patient appropriateness/Referrals	<p>Codes refer to issues specific with the scope and definition of palliative care vs hospice</p> <p>“where do you kind of draw them line and sort of what</p>	<p>don't know how to label patients</p> <p>palliative care is appropriate ... everybody in the hospital</p> <p>shift the continuum relabeling it as a palliative care</p>

		<p>patients are palliative, which patients are really in more of a chronic pain management situation?”</p> <p>“I worry if that will shift the continuum where we do get an exception because our patients do have a different need. If we just label everybody that has chronic pain now has a palliative need, then I think that we're really potentially doing a disservice to patients that have serious illness.”</p>	<p>no longer curative intent So it all goes to palliative care. Pain doctors Referrals they're less recalcitrant to have palliative care is on board we'll do palliative management to manage your symptoms well we'll just get somebody to come to your house</p>
	Regulatory Influence: Protections vs Pressures	<p>Codes refer to the perception of the clinician that they are protected regulatorily due to policy exclusions with opioid prescribing in hospice and palliative care.</p> <p>“the guidelines specifically exclude palliative care and they use the word palliative care. Um, so, um, I feel like I personally and professionally and protected because I</p>	<p>professionally protected They're not looking at hospice doctors these people that are dying didn't have the umbrella that would protect him. specifically excluded doesn't apply to the STOP Act stop prescribing swung the pendulum a little too far regulatory body is going to sweep in the government would be after them fear of...the DEA</p>

		<p>have a board certification in palliative care.”</p> <p>“the STOP Act. Sounds pretty scary, doesn't it? Like the STOP Act, you know, stop prescribing is the message I get from that, but I'm not going to stop prescribing.”</p>	<p>pendulum has swung carve out that line numbers are being tracked and reported they're getting official letters</p>
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